

## Chapter 3 | Underserved Consumer Interviews

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PRELIMINARY | Still Under Review

### UNDERSERVED CONSUMERS SPEAK: IN-DEPTH YOUTH, FAMILY MEMBER, AND CONSUMER INTERVIEWS

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#### ABSTRACT

As one component of Washington's Needs Assessment and Resource Inventory, the Washington Institute for Mental Illness Training and Research (WIMIRT), in partnership with the University of Washington Division of Public Behavioral Health and Justice Policy (DPBHJP), completed an *In-Depth Youth, Family Member, and Consumer Interview Project*. Consumers, family members of consumers, and young people who have received support for mental health issues were trained as interviewers and interviewed total of N=126 consumers, youths, and family members. In addition to serving as a mechanism for consumers of mental health services to participate in research, the Consumer Interview Project was specifically intended to get perspectives from persons who experience mental health problems who either (1) do not access supports from the formal mental health system, or (2) were likely to be underrepresented in other data collection.

Qualitative data from interviews were analyzed by abstracting unique statements from interview records and sorting them into major themes. Results yielded common themes from across all the consumers interviewed, as well as themes about the mental health system and its transformation that were specific to certain groups. Across all interviewees, the following themes were common:

- Access to care
- Having choices
- The need for service integration and coordination
- Help with co-occurring disorders
- The presence of stigma
- Needing someone to listen

However, there were also themes that were specific to certain groups. Not surprisingly, **homeless individuals** were adamant that support for their mental health issues required assistance with jobs and housing. All 33 homeless individuals that were interviewed had an experience similar to one 35 year old African American male: A victim of child abuse, he described suffering from anxiety and post traumatic stress syndrome. Even though he's been clean and sober 8 years, he's unable to find a job or housing. He's on the waiting list for housing, which is 8 to 9 months long. He wants and needs a home and a job with coaching, he wants to be safe.

**Spanish speaking individuals** expressed the need for culturally relevant and language appropriate help. In one example, an eighteen-year-old Spanish-speaking female who attends high school has been severely depressed and tried to commit

suicide once. She is the daughter of migrant workers and has worked in the fields since she was 13. She was diagnosed with PTSD after being raped by two older males. She told our interviewer: "I would like to see more mental health available for teenagers with depression, because they do not know how to cope with it. Help teens with problems that can bring depression. The services should be in both languages, English and Spanish."

**Youth** expressed very clearly a need for help dealing with trauma and rape. One youth expressed the frustration of not being able to access help for the debilitating aftereffects of her previous sexual exploitation. Others expressed that it seemed the only way to make the system pay attention to your needs was to get pregnant or get arrested.

**Family members of youth** expressed a need for getting support, such as from peer professionals, and access to as much family empowerment as possible. They also frequently cited the stigma of having a child with mental health problems. Coordination of services, such as across child welfare, health, and school settings was viewed as a critical need for many family members of youth with mental health problems.

For **older adults**, it was frequently expressed that it is very important that they are treated with dignity and respect. Older adults share a common theme with youth, the desire to have someone really listen to them. In addition, the need to be able to have coordination of care across health and mental health providers was an oft-expressed need of older adults.

## INTRODUCTION

From April – June, 2006, the Washington Institute for Mental Illness Training and Research (WIMIRT), in partnership with the University of Washington Division of Public Behavioral Health and Justice Policy (DPBHJP), completed an *In-Depth Youth, Family Member, and Consumer Interview Project*. This endeavor aimed to complement the collection of data via consumer phone interviews and agency administrator and Regional Support Network interviews by gaining perspectives from consumers of mental health services about the current state of the mental health system and needed improvements. The project also served as a means for Washington State's mental health transformation grant to live up to its goal of meaningful involvement of consumers in research and data collection, as all interviewers employed in the project were current and former consumers of mental health services. Family members of consumers and young people who have received support for mental health issues were also trained and participated as interviewers.

In addition to serving as a mechanism for consumers of mental health services to participate in research, the Consumer Interview Project was specifically intended to get perspectives from persons who experience mental health problems who either (1) do not access supports from the formal mental health system, or (2) were likely to be underrepresented in other data collection. The goal for data collection was to inform planning and program development and ultimately to improve the quality of mental health services delivered in the state.

Data from the interviews were presented to the Mental Health Transformation Work Group on June 16, 2006. The current report will follow the basic format of the presentation and include:

- A brief description of the methodology employed;
- Demographics of interviewees;
- Results of qualitative analysis of interviews;
- Themes and issues raised by specific demographic groups; and
- Sample representative quotes from interviewees, organized by major themes.

## METHOD

**Measure.** Interviews consisted of two main sections. The first section included the four primary questions posed across multiple components of the NA/RI:

1. *Within the Washington State mental health service structure, what, in your opinion, is working well?*
2. *Within the Washington State mental health service structure, what, in your opinion, is NOT working, creates barriers, or fails to provide quality service and support?*
3. *From your perspective, what would a transformed mental health system look like?*
4. *What outcomes would indicate the system has transformed/changed in positive ways?*

Second, interviewees were provided with prompts to help them reflect on Washington State's current conformance to the 6 President's New Freedom Commission for Mental Health Goals:

1. Residents of Washington State understand that mental health is essential to overall health
2. Mental health care is consumer and family driven
3. Disparities in mental health services are eliminated
4. Early mental health screening, assessment, and referral to services are common practice
5. Excellent mental health care is delivered and research is accelerated
6. Technology is used to access mental health care and information

Interviewers were trained to gather information about these 10 questions in conversational format, starting with a description of the respondent's own experiences seeking help for mental health issues, and then presenting prompts to gain information about the subject matter presented above.

**Procedure.** Interviews were conducted by 14 consumers with ties to mental health consumer advocacy organizations, Regional Support Networks, provider organizations, clubhouses, and other entities at which consumers of mental health services can be accessed. These consumers were trained by WIMIRT staff via an all-day training, and were provided with a set of interview questions and a coding sheet on which to capture responses.

Respondents were recruited via a modified snowball sampling approach. Consumers and family members known to the interviewers and associated with their organizations were approached to complete interviews. These respondents then nominated additional consumers and family members who might be interested in completing interviews.

Interviewers were asked to focus recruitment on members of several stakeholder groups expected to be underrepresented in NA/RI activities, including:

- Young people (age 15-24)
- Family members of consumers
- Incarcerated adults and youths in juvenile justice
- Spanish-speaking individuals
- Native Americans
- Older Adults
- Homeless individuals
- Lesbian, gay, bisexual and transgender individuals
- Veterans
- African Americans
- Individuals with co-occurring disorders

Interviewees were given a \$20 gift card to Safeway or Fred Meyer as an honorarium.

**Data analysis.** Data analysis was conducted by abstracting unique statements from respondents' interview records and sorting each statement into unique themes arranged by the major areas of interest. These areas included the four main transformation grant-planning questions presented above and the six New Freedom Goal areas.

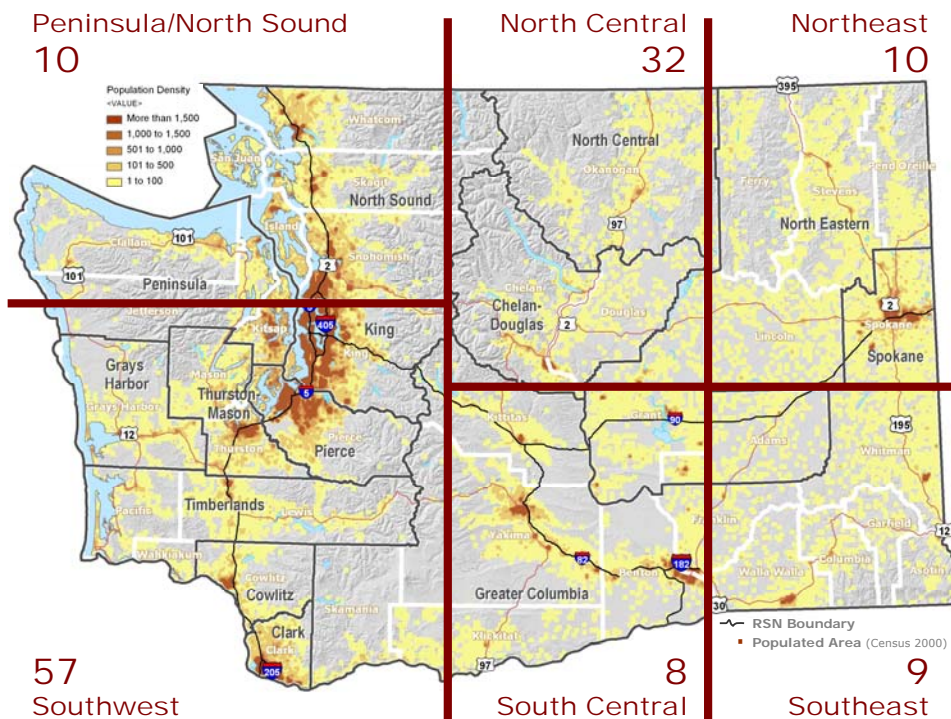
In addition, consumer leaders from WIMIRT and consumer, youth, and family member interviewers reviewed interview records to extract major themes of responses from specific demographic groups with adequate response rates to support such analyses. Such separate analyses were ultimately conducted for five special groups, including homeless individuals, Spanish speaking individuals, youths, family members of consumers, and older adults.

## Results

### Demographics

A total of 126 interviews were completed by the research team. The research team aimed to achieve a sample of consumers, youth, and family members that was geographically representative of the population of Washington State. This aim was fairly well achieved: Approximately 45 percent of the interviews came from residents Southwest Washington, most from the King, Pierce, and Clark County areas. (Approximately 48 percent of the population of Washington State resides in these counties.) North Central Washington, a geographic area often observed to be underrepresented in past data collection efforts, was also highly represented, with approximately 25 percent of interviews completed in Chelan and Douglas Counties. The remaining 30 percent of the interviews were completed in Northwest, Northeast, South Central, and Southeast Washington. (See map below for more complete details.)

### Distribution of Interviewees Participating in the In-Depth Youth, Family Member, and Consumer Interviews



MAP SOURCES: 2003 Sub-County Population Estimates by Washington State Department of Health, Vista Partnership, Krupski Consulting; Washington State Population Estimates for Public Health. October 2004. CHART by DSHS Research and Data Analysis Division, May 2006.

Forty six percent of respondents were male and 54 percent female. With respect to the diversity of age, cultures, and ethnicities: 46 percent of respondents were Caucasian, 24 percent Latino, 14 percent Native American and 8 percent African American. Seventy percent of those interviewed fell between the ages of 26-55, while 15 percent of respondents were youths (age 15-24) and 15 percent were older adults (age >56). Efforts to target other populations perceived to be under-sampled in the NA/RI yielded a sample that included 38 percent individuals experiencing co-occurring disorders, 27 percent family members, 26 percent homeless individuals, 24 percent Spanish speaking persons, 17 percent persons involved with the criminal justice system, 14 percent Native Americans, 8 percent veterans, and 4 percent persons who self-identified as sexual minorities. (See Tables 1 and 2 below.)

Table 1. Demographics of Respondents			Table 2. Other Characteristics		
GENDER	N	%	INSURANCE	N	%
Female	68	54%	Medicaid	48	38%
Male	58	46%	CNP	5	4%
			L & I	1	1%
AGE	N	%	IHS	2	2%
0-14	3	2%	Private	20	16%
15-24	17	13%	Medicare	11	9%
25-55	88	70%	None	39	31%
56 +	18	14%			
ETHNICITY	N	%	OTHER CHARACTERISTICS	N	%
Caucasian	66	52%	Military/Veteran	10	8%
Latino/Hispanic American	30	24%	Incarcerated Adult	12	10%
Native American	18	14%	Juvenile Justice	9	7%
African American	10	8%	Homeless	33	26%
Other	2	2%	Co-occurring	48	38%
			Sexual Minority	5	4%
			Family of child/youth	34	27%

Overall, 31 percent of consumers reported they had no health insurance, which also constituted a population of interest not able to be sampled via the consumer phone interviews component of the NA/RA. Of those that currently have insurance, approximately 55 percent use Medicaid, while only 13 percent of those with coverage utilize private insurance.

## Representative Quotes from Interviewees

The diversity of opinions and voices ultimately interviewed by participants in this project makes it difficult to present overarching recommendations or needs. Given that a major goal for the project was to inject the perspectives of individuals who experience mental health issues but who are rarely approached to provide their opinions, the following section presents representative quotes that are salient to the 10 major areas of inquiry. Some of the following quotes are in the words of the respondents, while some are in the voice of the interviewers, who themselves were chosen to participate in the project because of their experiences as consumers of services provided by the mental health system.

### QUESTION 1: What is working well?

- "The bright part of her life is that her therapist recognizes and has educated her regarding post traumatic stress disorder and she no longer blames herself for her depression and inability to feed or cloth herself from day to day."
- "After six months of care and much experimenting with medication, my daughter was released to our family with a prescription and a bright future ahead of her."

Her diagnosis was bi-polar II. I would estimate that the cost of her care at just under \$125,000.”

- “Downtown Emergency Services Center is a 12 out of 1 to 10.”
- “Downtown Emergency Service Center staff really care; they would lie down on the street with you if that what they needed to do to talk with me.”
- “DESC respects my culture.”
- “I have a great counselor and periods of wellness and I have some financial coverage now, but not enough for all my need.”
- “Eastern State Hospital is working well and the people are really nice and try to educate people about their illness.”

## QUESTION 2: What is not working?

- “It was a whole lot better here on the streets than any other place I had been so far.”
- “She moved to her current home city so that she could be closer to her mother and have an extra pair of hands to help with her son. Unable to find work, she once again received financial assistance from welfare.”
- “I just wish it would be easier to get in counseling such as if I got a referral from my doctor and I can go straight to the counseling office.”
- “The judge took one look at the case and said ‘What’s this guy doing in jail? He should never have been in jail. The Police Department should have taken him directly to the hospital so he could be committed’.”
- “Our hospital diversion is a joke, a patient can walk right out of there and MHP’s don’t have to let anyone know, either family or police. We had to live there in order to make sure my wife was ok.”
- “We keep coming back for services at the jail because there is never any improvement in our conditions. ”
- “We may stabilize but we do not receive the education and treatments to keep us out of here.”
- “Families need to be educated so they understand we have an illness and they can help support us.”

## QUESTION 3: A transformed mental health system

- “. . . give hope to people & not make them feel like their isn’t anything they can do except drink”
- “Make work programs available to the homeless.”
- “Vulnerable people should not be living on the streets or in a shelter.”
- “I would like to see more housing, jobs and competent providers.”
- “Excellent mental health care would include being able to see a psychiatrist within a week, get started on medication regardless of cost, more safe housing that is nice.”
- “The whole family would be the client and respected as such. The family cares for the person usually 7days a week and yet the people who supply the most care and are the most affected are invisible to the mental heath system and treated with contempt or disgust.”
- “It is my hope that the 13.5 million dollars spent over 5 years will produce outcomes and not just a bunch of meetings that give recommendations that never happen.”

- “I would like to be met at the door of the jail (when released) and have someone help me find a home and a part-time job.”
- “I would like services that are family friendly and the people with these services to realize that when a person is so sick they can’t function how can they expect them to understand and fill out forms and sign them.”

#### **QUESTION 4: Outcomes indicating system change**

- “All mentally ill people should have a home.”
- “I would also see CDMHP’s commit jailed individuals from jail to the hospital that are jailed for mental health reasons and shouldn’t have been there in the first place.”
- “There would be good training and community awareness.”
- “An excellent mental health system would have fast response, equal access, same day crisis treatment, immediate education, therapists, and overall wellness and preventive system.”

#### **GOAL 1: Stigma in Washington State**

- “I fear asking for mental health because I don’t want people to think I am crazy I really am not scared of asking for medicine at the doctors but I am scared of DSHS.”
- “People say derogatory things about mentally ill people all the time. It never stops.”
- “My ex-husband was physically abusive to our son, and he was in danger but it still took an act of God to get him back because I had been in a mental hospital for 13 days.”
- “There is no education. We need to do a campaign like they do to stop smoking.”

#### **GOAL 2: Choices and Ownership in Mental Health Care**

- “I have not had an experience when I felt empowered.”
- “Create services for homeless Spanish speaking individuals and families.”
- “Each time he has left a job, it is because of his search for better medical coverage.”

#### **GOAL 3: Accessibility of Services**

- “There is no help for people like us, can’t even see a doctor when we need one. All I can get is a probation counselor who tells me what to do, and what not to do”
- “She is not receiving counseling from any mental health facility because of the difficulty she experienced attempting to enter the system”
- “DSHS told her that she couldn’t get help unless she got knocked up or was really psycho”
- “They had too many people on the waiting list for the week I asked for help so I got some friends to help me out by getting me my drug of choice”
- “Help for migrant workers because they work hard, pay taxes just like anybody and they do not have benefits.”
- “I would like to see more mental health available for teenagers with depression, because they do not know how to cope with it. Help teens with problems that can bring depression. The services should be in both languages, English and Spanish.”

- “He has given serious thought to divorcing his wife, declaring bankruptcy, gaining sole custody of his child and getting on welfare just to get his son the care and education that he knows he needs.”
- “The jail is my usual form of hospitalization.”
- “Maybe it’s my fault, maybe I could not communicate how really bad I was. Sometimes I don’t tell how bad I am because I want the medicine without being locked up.”

#### **GOAL 4: Seeking Help**

- “Counselors need more time to spend with people, not be so hurried.”
- “My experience is you give up so much of yourself when receiving services or help, and have so many people in your life telling you about all the things they think are wrong about you.”
- “The staff is very good with me. I like being in charge of my life and taking care of myself.”
- “Find people that care about people to work in the system.”
- “Have case managers who care about Spanish speaking people”
- “I feel that they (various services) never coordinate; one tells me one thing and another tells us something else.”

#### **GOAL 5: Quality of Care**

- “Need a place where old people will be accepted for being late, forgetful, tired, not sure, scared, lonely, needing meaningful activities.”
- “Just need someone to remember I’m here even if my husband is gone.”
- “My culture is not respected; they (mental health staff members) look frustrated because we don’t understand what they say.”
- “If I could have one thing immediately it would be a local hospital. We have to stop traumatizing the mentally ill by putting them in jail with inmate criminals.”
- “I would pay the staff more money so we can have qualified people.”

#### **GOAL 6: Research and Technology**

- “I was impressed with the trend toward Evidence-Based practice”
- “I receive information from NAMI and how to integrate the mentally ill better into the community.”
- “I access information from NAMI Library and I like to learn about the interaction of psychiatric drugs and alcohol.”
- “I used the internet on a friend’s computer to look up stuff.”

### **Results of Qualitative Analysis of Interviews**

#### **Summary of Responses to Questions about Mental Health Transformation**

Table 3 presents results of a qualitative analysis of responses given by individuals interviewed regarding the current strengths, weakness, and needs for improvement of the Washington State mental health system. Overall, many of the themes remained constant throughout the questions asked of respondents. As such, responses to the

four primary Needs Assessment questions were analyzed as a whole. A summary of findings is presented below:

- The most frequently cited **helpful services** were **access to medication through mental health and non-mental health settings, drop in centers/shelters, and support groups**.
- Some individuals felt that their needs were being met, mentioning client-doctor meetings as particularly effective. However, many consumers felt that they were **unable to access necessary care**. The long processes (i.e., “red tape”) that it takes to get into services were mentioned as a barrier. Access to care needs improvement, especially before people are in crisis.
- **Lack of housing and financial stress on individuals and families** was discussed consistently across interviewees, suggesting a need for such basic services being provided as well as mental health treatment. Consumers cited improvement in the ability of the system to provide such basic services as an indicator that progress was being achieved in creating a transformed mental health system.
- System issues included an overall **lack of understanding of mental illness**, the tendency for individuals with mental health issues to **cycle through the legal system**, and a **lack of continuity between workers throughout the course of treatment**. Consumers recommended that all departments (i.e., DOJ, JRA, DASA) work together for the betterment of the individuals that they are serving.
- Consumers suggested that more funding be provided to offer a variety of **crisis services** (i.e., for adults, children, families, partners) which would be available 24 hours a day, 7 days a week, as well as more frequent involvement of family members in treatment.
- Populations seen as **lacking services** included **Spanish-speaking individuals, children, the working poor who may not have Medicaid, and the homeless**.
- Many people commented that they felt they were receiving **excellent care**, citing **case managers, primary care physicians, counselors**, and other organizations providing **peer support**.
- Assistance for clients **outside of typical counseling services** were also suggested, including such topics as helping with benefits, assisting with housing and employment, and help with remembering appointments.
- It was recommended that consumers be provided with more counselors who were equipped to provide better service due to a **decrease in caseloads, increase in pay, and provided with more training**. Additionally, consumers would like a greater say in the treatment they receive.
- Among the many outcomes that consumers would like to see with regard to a transformed mental health system, the most commonly mentioned issues included: a **decrease in homelessness and hospitalizations**, a **more positive spin on mental illness in the media**, **less police involvement**, **more public education**, **less wait time** for an appointment, and **financial assistance** available to everyone.
- For **youth** specifically, consumers posed several specific positive outcomes of a transformed system, including **increase in the number of young people graduating from high school and a decrease in the arrest rates of youth**.
- Outcomes for adults and families were providers working in the best interest of the family overall, rather than just the individual being treated.
- Outcomes related to **older adults** included older adults being treated with greater respect by the system and providers.

Table 3.

### Results of Qualitative Analysis of Mental Health Transformation Questions

Themes	N Statements
<b>What is Working Well?</b>	<b>113</b>
<b>Helpful Services</b>	<b>44</b>
Access to medication through mental health and non-mental health settings	9
Drop in shelters	5
Support groups	4
Children's programs	3
NAMI	2
Family to Family and Peer to Peer	2
Parenting classes/support groups	2
The Behavioral Health Clinic	1
CIT for the police	1
The Promise Club	1
Kwawachee	1
The 211 service that is now available	1
Services that combine religion and psychology	1
Group homes have provided good service	1
MICA in Puyallup	1
Youth emergency services support group	1
Good Samaritan	1
Home-based community services	1
Alcoholics Anonymous	1
Crisis Line	1
CORE	1
DRA	1
Mental health services	1
Advance living skills programs	1
<b>Who is Helping?</b>	<b>40</b>
Primary Care Physicians	10
Case Managers	8
Counselors	7
Clubhouse	4
Peer counselors	4
Eastern State Hospital	3
Parent advocates	1
Fairfax inpatient	1
DESC	1
Caretakers assigned to DD youth	1
<b>Positive Experiences</b>	<b>15</b>
Feel that needs are being met	10
Doctor/client meetings are positive	4
Has more access to services now than in the past	1

<b>Systems</b>	<b>8</b>
The community/public health system	3
The legal system (i.e., jail and juvenile detention)	3
The mental health system	1
The RSN system (most of the time)	1
<b>Negative Experiences</b>	<b>6</b>
Felt that needs have not been met	5
Was mistreated by staff	1
<b>What is Not Working?</b>	<b>125</b>
<b>Overall</b>	<b>49</b>
Unable to access necessary care	16
Long processes ("red tape") to get services	6
Providers don't always care about what happens to their clients	4
Lack of safe shelters/housing	4
Financial stress on individuals and families	4
Lack of understanding of available services	4
Nothing is working well	3
Counselors cannot spend enough time with clients	1
Not enough community activities	1
Not enough options for older adults	1
Doctors blame clients for drug use	1
Unwelcoming services	1
Everything is working well	1
People don't always fit into the categories provided	1
Lack of follow through by providers	1
<b>System Issues</b>	<b>44</b>
Lack of understanding of mental illness	9
Lack of continuity between services and individual workers	8
Individuals cycling through the jail system	6
No access to care in rural communities	4
Youth going to jail instead of the emergency room for services	3
The RSN governing board does not govern for the good of the community	2
Lack of employment opportunities	2
No access to ongoing care (i.e., always has to use crisis services)	2
Medicaid does not provide access to a variety of services	2
Racism within the system	1
CPS called when parents try to access help	1
Not enough respite services with appropriate care	1
Funding cuts are eliminating necessary programs	1
People are cut off of SSI	1
Not enough activities to help with recovery	1
<b>Solutions</b>	<b>18</b>
Involve family members and friends in treatment	6
More education on mental illness	5
Need self-help and support groups	2
24 hour access to care	2

Hire more people of color at the programs	1
Provide insurance coverage to everyone	1
Provide more than just medication for treatment	1
<b>Populations Lacking Services</b>	<b>14</b>
Spanish-speaking individuals	6
Children	4
Homeless individuals	3
The working poor	1
<b>Features of a Transformed Mental Health System</b>	<b>152</b>
<b>Specific Suggestions</b>	<b>65</b>
Safe housing available	14
24 hour access to care	9
More services in rural towns	8
Assistance for clients outside of counseling (i.e., with benefits, remembering appointments, finding a job/housing)	5
Education around mental illness	4
Inform people of available programs	3
Counselors would have more time with clients	3
Sliding fee services	2
Evaluation of systems conducted regularly	2
Intake would take no more than 20 minutes and would be meaningful	2
Consistency of counselors throughout treatment	2
Have more doctors who focus on specific diagnoses	2
Mental health worker in every school	1
Need opportunities for education	1
Provide peer counseling services	1
Consumers occupying top mental health system positions	1
A Mega Clinic with different departments for each mental illness	1
Local detox center	1
More programs for co-occurring, life skills, etc. available	1
Culturally and linguistically appropriate services	1
Should be able to detox voluntarily	1
<b>Service Level</b>	<b>43</b>
Pay attention to concerns of family members and friends (esp. parents)	10
More counselors equipped to provide better services	9
Clients need to have a say in their treatment	6
Earlier recognition of symptoms	3
People would know what services are available	3
Would not have to have severe symptoms in order to receive services	3
Client would come first	2
Not having to wait for appointments	2
Provide most up to date care	1
More services for young children	1
Counseling and medication available together	1
More follow-up care	1
Better understanding of children's mental health	1

<b>System Level</b>	<b>38</b>
Improve access to care (spec. pre-crisis)	18
Financial ability would not be an issue in receiving treatment	6
All departments (DOJ, JRA, DASA, etc.) working for betterment of person	5
Provide good jobs for people	3
Give people treatment, rather than sending them to jail	2
Healthcare for everyone	1
Awareness in government	1
There should be no wrong door	1
School personnel need to play a bigger role	1
<b>Personal Level</b>	<b>5</b>
Individuals would be known for traits other than their illness	1
Children need people who will love and care for them	1
People need to believe that they can get better	1
No one would be judged as unable to treat	1
Clients need to feel useful and productive	1
<b>Regarding the Transformation Grant</b>	<b>1</b>
The money spent to improve the system should not be wasted on a bunch of meetings and no outcomes	1
<b>Outcomes Indicating System Change</b>	<b>86</b>
<b>Generic Outcomes</b>	<b>34</b>
Decrease in homelessness	7
Positive spin in the media	6
People would be educated with regard to mental illness	6
Mental illness is seen as "normal illness"	2
There would be no stigma	1
When people can get help on demand	1
Quicker access to services	1
Increased number of people able to work	1
Service provided for everyone	1
Fewer suicides and suicide attempts	1
Less people traumatized by mental illness	1
People able to lead fulfilling lives	1
Thinking outside the box is valued	1
More people doing what they love to do	1
Less news about people harming themselves or others due to mental illness	1
Fewer community problems	1
No more complaints about the mental health system	1
<b>System Outcomes</b>	<b>32</b>
Less police/jail involvement	6
Less time to wait for an appointment	4
Financial assistance available for everyone	3
Decrease in hospitalizations	3
Keep one therapist/case manager throughout treatment	2
Effective mental health facilities where they are needed	2
Better training for mental health workers	2

More people included in the "system"	2
Every person would have health coverage	1
Increase in federal funding	1
Early screening for everyone	1
More staff and lower caseloads	1
Decrease in incarceration of people with mental health issues	1
Increased number of people enrolling in services	1
CIT would be mandatory for all police officers	1
Service availability/information would get to potential consumers	1
<b>Outcomes Related to Youth</b>	<b>12</b>
Children growing up to be loving and self-supporting	2
More kids graduating from high school/college	2
Less number of teens being arrested	2
Youth with problems identified earlier on	1
Youth would have more of a voice	1
Fewer teenage suicides	1
Youth able to access mental health services in schools without stigma	1
Happier kids and fewer hospital stays	1
Less number of teens being sent to foster care	1
<b>Outcomes Related to Adults/Families</b>	<b>6</b>
Facilities working for the best interests of families	2
Divorce rates for parents with mentally ill children going down	1
People would be working and happy again	1
Decrease in family dysfunction	1
Less people on public assistance	1
<b>Outcomes Related to Older Adults</b>	<b>2</b>
When older adults are treated as well as everyone else	1
Seniors shouldn't have copays	1

## Summary of Responses to Prompts about the Six New Freedom Commission on Mental Health Goal Areas

Table 4 presents results of a qualitative analysis of responses given by individuals interviewed regarding Washington State's achievement of the six New Freedom Commission Goals. The following summary presents some of the main themes, concerns, and suggestions provided by individual consumers in response to prompts about the 6 New Freedom Commission Goals. Many of the ideas correspond with those from Table 2, as they are essential to changing the mental health system. A summary of findings is presented below:

- The **stigma** of having a mental health issue, or a family member with a mental health issue, affects one's ability to get jobs, maintain custody of children, parents ability to be involved in their child's education, and overall ability to feel safe asking for the help they require.
- A primary theme with regard to the stigma experienced by consumers and their families is the **need for public education** about mental health issues, especially for teachers and other professionals involved in assisting this population. Also mentioned was some form of **education within the school system** to help combat the stigma associated with youth who have mental illness.

- Many consumers recommend that **housing** be provided for all individuals as a baseline need. They identified that it is difficult to treat people with mental health issues if they are lacking basic necessities.
- **More coordination** is necessary between services, agencies, and providers in order to provide quality care to consumers. Continuity of providers throughout treatment was also mentioned as a necessary change (i.e., not switching providers every couple of months).
- **Culturally and linguistically appropriate services, services in rural communities, and specialty services** such as access to psychiatrists, were identified as lacking throughout the interviews.
- The **length of time** that it took to become involved in services was an issue for many consumers. Locating a provider, going through the intake process, being assigned to a clinician, and beginning treatment were just a few steps mentioned as barriers to accessing services. This process can take several months at times and is not conducive to assisting people when they actually need the help.
- The need for **greater access** was discussed. Many individuals go through the emergency room, their church, or jail to receive services. Children often become ineligible for services based on age constraints, and the family is then left to find new services.
- **Financial constraints** placed on families, including **issues with insurance**, were common. It was recommended by several consumers that the state provide healthcare to every person, regardless of income or job status. Overall, it was recommended that **mental health care be more affordable and accessible**.
- People did report that they felt they were receiving excellent care, although several did feel that the care they received had been very poor. Consumers mentioned that it would be helpful to have an **advocate to navigate the system** with them.
- Consumers offered a variety of **suggestions for future research**, focusing mainly on the reasons for different diagnoses and options for treatment. The **internet** was cited as being useful for many consumers, although several mentioned that they did not have the access or experience to utilize the information found online.

Table 4.

#### Results of Qualitative Analysis of Responses Regarding New Freedom Commission Goals

Themes	N Statements
<b>Goal 1: Recognizing that Mental Health is Essential to Overall Health: Stigma in Washington State</b>	<b>104</b>
<b>Solutions</b>	<b>36</b>
Educate physicians, teachers, and the public to reduce stigma	15
Incorporate anti-stigma education into schools	7
Promise, NAMI Club, Clubhouse, and life skills are helping with stigma	5
Respect for all individuals with mental illness	3
Positive representation in the media	3
More coordination between service agencies	1
Youth In Action program	1
Provide housing for all homeless individuals	1
<b>Diagnosis and Treatment</b>	<b>26</b>
Feel comfortable talking with their doctor/nurse/counselor	12
Physicians often require physical symptoms before examining mental ones	2
More difficult in rural communities to receive treatment due to stigma	2

Need accurate diagnoses that don't label people	1
Depression is not seen as a mental illness	1
Counselors blame parents for their child's diagnosis	1
Definite stigma attached to diagnosis of autism	1
Need to address issues other than just treatment (i.e., homelessness)	1
Medical discharge from the military creates stigma	1
Medication use increases the stigma	1
Incarceration due to mental illness creates stigma	1
People feel judged for past abuse they may have experienced	1
Difficult to gain custody of children because of stigma	1
Pay attention to cultural implications of diagnosis and treatment	1
<b>Life Without Stigma</b>	<b>31</b>
No one would have to hear unkind remarks	24
Everyone would feel safe asking for help	5
Parents wouldn't fear that their child would be taken away	1
Parents would not have to worry about what people think of their child	1
<b>Issues in the School System</b>	<b>6</b>
No tolerance policies allow schools to "get rid" of mentally ill kids	2
Schools unwilling to work with autistic children	1
Parents do not feel safe asking for help from the school system	1
Kids who act out due to mental illness are blamed for their actions and refused 504's	1
Assumed that parents do not want to be part of kids' education	1
<b>Lack of Consumer Awareness</b>	<b>5</b>
Consumers unable to see how their behavior might be caused by mental illness	1
Although antidepressants may be working, consumer feels that they are still just a little tired rather than depressed	1
Refusal to take medication due to feeling labeled	1
Consumer feeling that their family is not susceptible to mental illness	1
People with mental illness often refuse to acknowledge that they need treatment	1
<b>Goal 2: Consumer and Family Directed Treatment: Choices and Ownership in Mental Health Care</b>	<b>84</b>
<b>Solutions</b>	<b>28</b>
Provide funding for support groups (for clients, parents, partners, etc.)	7
Funding for NAMI programs	4
Coordination of care between providers	3
Involve multiple systems in care	2
Provide local detox center	2
More services for homeless people	2
Provide care for co-occurring disorders	2
Provide evaluation and treatment center that is available 24/7	2
Transportation to and from services	2
More respite care opportunities	1
Provide mental health treatment for people coming out of jail	1
<b>Lack of Choices</b>	<b>27</b>
No choice in the type of therapy consumers can receive	10

Able to receive help when needed	7
Need culturally, linguistically appropriate services (especially in rural areas)	4
Not many psychiatrists to choose from	4
Parents have few choices for their children's treatment	2
Getting help is always a choice, unless enforced by the legal system	1
<b>Lack of Resources</b>	<b>21</b>
Financial constraints experienced by families	9
Insurance only covers some services	6
Therapy generally too time-constrained	2
Lack of funding provided to mental health services	1
More programs in rural communities	1
Make people aware of available resources	1
More housing, jobs, and competent providers	1
Caseworkers have been extremely unhelpful	1
<b>Treatment Issues</b>	<b>8</b>
Often there are too many individuals involved in providing mental health care (i.e., different counselor for each issue)	3
Counselors receive limited information from the client	2
Treatment is not empowering	2
Does not want treatment for illnesses	1
<b>Goal 3: Reducing Disparities and Increasing Accessibility of Services</b>	<b>67</b>
<b>Barriers to Accessing Services</b>	<b>37</b>
Services are culturally inappropriate	12
Insurance only covers certain services	6
Services take too long	5
Financial constraints of family	4
Never attempted or does not want to access services	3
Unable to seek care due to logistical reasons (i.e., no phone, no language resources, insurance difficulties)	3
Very few services/providers available	2
No access to necessary services for older adults	1
Felt that they would be judged when seeking help for their illness	1
<b>Methods to Obtain Access</b>	<b>18</b>
Go to the emergency room	5
Through church	4
Seeks help through family members	3
Get services by going to jail	2
Through doctor	1
Be persistent and assertive in order to receive services	1
Became homeless to receive services	1
Accessibility has never been an issue	1
Use DD to access services	1
<b>Awareness of Resources</b>	<b>5</b>
Unsure what services are available	2
Never been refused services	2
After years of dealing with the system, finally know where to get services	1

<b>Solutions</b>	<b>4</b>
More crisis services	3
Provide counselors and Ph.D.'s	1
<b>Problems with Intervention</b>	<b>3</b>
Often received too late	1
Therapeutic foster care is not set up for mentally ill youth	1
Bypasses least restrictive care setting	1
<b>Goal 4: Early Intervention and Getting Rapid Access to Help</b>	<b>35</b>
<b>Barriers to Seeking Help</b>	<b>22</b>
"Getting in" to see someone takes a long time	8
Unable to see need for services right away	5
Lack of or inadequate screening and diagnosis	4
Ages of children; services no longer available after a certain age	1
Treatment offered is insufficient compared to need	1
Systems unable to quickly decide on coverage/payment for services	1
Lack of services for children	1
Culturally and linguistically appropriate services unavailable	1
<b>Positive Experiences</b>	<b>8</b>
Crisis services provide help quickly	4
Use of friends and/or family for help	2
Case manager very helpful	1
Felt empowered during triage process	1
<b>Referral Sources</b>	<b>5</b>
School system referred family to services	2
Jail	1
Family had to seek out services	1
Primary Care Physician	1
<b>Goal 5: Quality of Care and Accelerated Research</b>	<b>92</b>
<b>Solutions</b>	<b>32</b>
Mental health care should be more accessible/affordable	9
Goal should be to help clients, not to get paid	3
Provide facilities that have medication management and assisted living	3
Provide more local resources (in rural communities)	3
Treatment driven by families and consumers	2
Doctors should acknowledge mental illness as a disease	2
Add more services and qualified clinicians	2
Consumer education regarding mental illness	2
Improved housing opportunities	1
Access to Job Coaches	1
Accessibility for everyone regardless of financial status	1
Provide wraparound services	1
Provide shelters specifically for dealing with mentally ill people	1
Funding to support families going through crisis	1
Community-based family practice that deals only with mental illness	1

<b>Positive Experiences</b>	<b>25</b>
Have received excellent care	23
Received helpful treatment while incarcerated (youth)	1
Eastern State Hospital is great	1
<b>Negative Experiences</b>	<b>16</b>
Received poor quality of care	4
Lack of respect for clients and family members	3
Lack of consistency between services/providers	3
Client or family dislike of services provided	2
Lack of cultural understanding	2
Too many gatekeepers	1
Has felt like a burden to their providers	1
<b>Program Suggestions</b>	<b>19</b>
Able to get in to see someone right away	5
Should be able to see a psychiatrist within one week	3
Better coordination between agencies	2
Helpful to have an advocate to help navigate systems	2
Pay staff better to ensure more qualified people	2
Provide continuity of care (always switching counselors)	2
Provide more services for young children	1
Schools should be set up do deal with kids with mental health issues	1
Make medication available immediately	1
<b>Goal 6: Research and Technology</b>	<b>87</b>
<b>Future Research Suggestions</b>	<b>27</b>
Study about different diagnoses	9
More options for treatment	3
Depression	3
Medications	3
Need more studies on self-harm	3
Compulsive thinking patterns	2
The causes of mental illness	1
Treatment for sexually abused children	1
Need research that focuses on finding answers	1
Would like to study the NARSAD impact	1
More research on natural alternatives	1
<b>Found Technology Helpful</b>	<b>25</b>
Internet has been very useful in obtaining information	22
Can receive information from a variety of methods now (i.e., email)	2
Able to make contact with other families via the computer	1
<b>Found Research Helpful</b>	<b>15</b>
Got information from the library	6
Has been helped by mental health research	5
Regularly accesses research via the internet	1
Gets information from MH conferences	1
Impressed with the trend toward evidence-based practice	1
Interested in forming a self-help group because of research	1

<b>Unable to Use Technology</b>	<b>14</b>
Does not have a computer or know how to use one	9
Most of the information available is in English	2
Prefers older methods (i.e., the yellow pages)	1
Cannot read or write	1
Never thought of using technology to access information	1
<b>Unable to Access Research</b>	<b>6</b>
Has no idea how to obtain information	2
Not able to read well enough to learn from research	2
Doesn't care about research	1
Unable to obtain information on how to help family member	1

## Major Themes from Specific Groups

A primary focus of the presentation by team members to the Transformation Work Group was to describe specific issues of concern for populations whose voices are perceived to be underrepresented. Such separate analyses were ultimately conducted for five special groups, including homeless individuals, Spanish speaking individuals, youths, family members of consumers, and older adults.

Consistent themes emerged in analyzing results of in-depth interviews from these groups, including:

- Access to care
- Having choices
- The need for service integration and coordination
- Help with co-occurring disorders
- The presence of stigma
- Needing someone to listen

However, there were also themes that were specific to certain groups. Not surprisingly, **homeless individuals** were unanimously insistent that support for their mental health issues required assistance with jobs and housing. All 33 homeless individuals that were interviewed had an experience similar to one 35-year-old African American male: A victim of child abuse, he described suffering from anxiety and post traumatic stress syndrome. Even though he's been clean and sober 8 years, he's unable to find a job or housing. He's on the waiting list for housing, which is 8 to 9 months long. He wants and needs a home and a job with coaching, he wants to be safe. It was stressed by consumers with homeless experiences that **jobs and housing** must be provided to consumers if recovery is truly a goal of the system. Many of these consumers made the point (supported by recent research) that the costs of subsidization of housing and providing job services would probably offset the costs of mental health and other care they often wind up receiving in hospitals and other emergency settings.

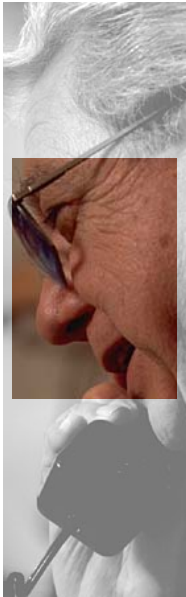
**Spanish speaking individuals** expressed the need for culturally relevant and linguistically appropriate help. In one example, an eighteen-year-old Spanish-speaking female who attends high school has been severely depressed and tried to commit suicide. She is the daughter of migrant workers and has worked in the fields since she was 13. She was diagnosed with PTSD after having experienced sexual assault. She told our interviewer: "I would like to see more mental health available for teenagers with depression, because they do not know how to cope with it. Help teens with problems that can bring depression. The services should be in both languages, English and Spanish."

**Youth** expressed very clearly a need for help dealing with trauma and rape. One youth expressed the frustration of not being able to access help for the debilitating aftereffects of her previous sexual exploitation. Several young people interviewed expressed that it seemed the only way to make the system pay attention to your needs was to get pregnant or get arrested.

**Family members of youth** expressed a need for getting support, such as from peer professionals, and access to as much family empowerment as possible. They also frequently cited the stigma of having a child with mental health problems. Coordination of services, such as across child welfare, health, and school settings was viewed as a critical need for many family members of youth with mental health problems.

For **older adults**, it was frequently expressed that it is very important that they are treated with dignity and respect. Older adults share a common theme with youth, the desire to have someone really listen to them. In addition, the need to be able to have coordination of care across health and mental health providers was an oft-expressed need of older adults.





## Chapter 4 | Telephone Survey of Consumers

JULY 2006

PRELIMINARY | Still Under Review

### MENTAL HEALTH CONSUMERS SPEAK

By The Washington Institute for Mental Illness Research and Training  
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#### ABSTRACT

**Data Sources:** This section was written using data collected by The Washington Institute. The content provides an analysis of the Recovery Oriented Systems Indicators (ROSI) Measure, the Discrimination Experience Subscale, and a series of open-ended questions that were developed collaboratively between the Washington Institute and other stakeholders. This section contains information on the dataset, a discussion of data collection methods, and additional information on data analysis.

**Survey Tool:** This report presents baseline data using a recovery tool called the Recovery Oriented System Indicators (ROSI) measure, a measure of perceived stigma, and open-ended questions addressing the four major Transformation questions.

**Service Satisfaction:** Overall, 70 percent of the consumers report being satisfied with staff and with mental health services they receive. However, most of the consumers do not believe that mental health services help them get basic resources such as employment and safe housing – services do not appear to be seen as helping them gain a sense of independence. Thirty-nine percent feel they are rarely or ever supported in getting the education or supports they and their families need to be fully supported.

**Access:** About 65 to 70 percent report that they can access services when needed. However, access and expanded services were the most frequently mentioned areas needing improvement. Twenty-four percent say they can rarely or never see their therapist when needed, and 13 percent can see them only “sometimes.”

**Stigma:** At least half of the respondents report feeling stigmatized and discriminated against because of their mental illness.

#### THE WASHINGTON INSTITUTE

##### ABOUT THE WASHINGTON INSTITUTE

The Washington Institute for Mental Illness Research and Training (Western Branch) is co-affiliated with the University of Washington and the Washington State Department of Social and Health Services, Mental Health Division. Our purpose is to improve collaboration between state government, colleges, and universities — and to conduct training, research, and clinical program development of direct benefit to persons with mental illness.

## HIGHLIGHTS | Research Methods and Questions Asked

### Key Questions

The current project is part of Washington State’s Mental Health Transformation effort and was developed to inform the following four major needs assessment questions:

1. *Within Washington State, what is working well when addressing the needs of mental health consumers?*
2. *Within Washington State, what is NOT working, creates barriers or fails to provide quality service and support when addressing the needs of mental health consumers?*
3. *What would a “transformed” mental health system look like?*
4. *What outcomes would indicate that the changes in the mental health service systems are creating improved results for consumers?*

### The Survey Questionnaire

To help answer these questions, a telephone survey of adult mental health consumers was conducted. Information collected by the survey includes demographics such as age, race/ethnicity, gender, and employment status. An instrument was also needed to measure consumers’ “recovery” within the mental health system. For this purpose, the Recovery Oriented System Indicators (ROSI) recently developed by Onken (2004) was included. This is a 42-item self-report questionnaire designed to assess consumers’ perception of what helps and what hinders mental health recovery within the mental health service system and ties directly to the four major needs assessment questions.

In addition to the ROSI, consumers were also asked questions about whether they felt stigmatized because of their mental illness. An example item is, “People discriminate against me because I have a mental illness.”

Seven more general questions were also developed to give consumers the opportunity to express their responses in their own words. These “open-ended” questions were posed in such a way as to reflect upon the four major needs assessment questions stated above. Examples include what they like most and least about the services they have received, and what the ideal mental health system would look like.

### ACKNOWLEDGEMENTS

#### A NOTE FROM THE AUTHORS

The researchers would like to express their sincere thanks to the interviewers who spent numerous hours attempting to contact potential respondents. With extraordinary diligence, the interviewers made thousands of phone calls in order to collect the valuable information used in this report— data that we hope will serve to help transform the way mental health services are delivered in Washington State.

Obtaining viable contact information for participants randomly chosen for this survey proved an onerous chore; this process required significant assistance from the 14 Regional Support Networks (RSNs) and scores of provider agencies throughout Washington State. The researchers would like to thank the RSN Administrators and their staff members for their efforts. We would also like to express our appreciation to countless staff members at the individual provider agencies for their patience and hard work.

Finally, the researchers would also like to thank Liz Kohlenberg and her staff at the Research and Data Analysis (RDA) Division for their assistance and quality of service in providing us with additional contact information.

## The Survey Sample

Consumers 18 years old and older that received state funded mental health services from June 1, 2005 to November 30, 2005 were the targeted population. Participating consumers were drawn from two sources, those receiving mental health services from state mental health providers (MHD provider group) and those receiving mental health services from other DSHS service providers that are not state mental health providers (non-MHD provider group). A simple random sample of 1,500 consumers was selected for each group. The samples came from the MHD MIS for the provider group and from the ACES Barcode (Economic Services) for the non-MHD provider group. This report represents 633 consumers who have participated in the survey, 384 from the MHD provider group and 249 from the non-MHD provider group.

## Survey Methodology

Survey data were collected using the Computer Assisted Telephone Interview (CATI) system. The CATI system integrates a questionnaire, databases, and a network of linked computers to allow interviewers to obtain information by telephone. Consistent with the intention of the Transformation Grant, most of the interviewers were themselves consumers of mental health services.

## Who Participated in the Survey?

Most survey participants were between the ages of 40 and 60 (50 percent). The second largest group was between 21 and 40 years of age (35 percent). Ten percent were 60 to 75 years of age. Three percent were under the age of 21 and only 2 percent were 75 or older. Those respondents in the non-mental health agency group were 4 years older on average than those in the mental health agency group. The majority of the respondents were female (65 percent) and most were white (77 percent). There was a fairly even distribution of Native Americans (5.1 percent), African Americans (5.6 percent), and Hispanics (4.7 percent). Asian or Pacific Islanders had the smallest representation (1.8 percent).

Of those who took the survey, 18 percent said that they were currently employed. The MHD provider group reported a higher rate of employment (16 percent) than the non-MHD provider group (11 percent). This difference may be due to the non-MHD provider group being older.

## HIGHLIGHTS | A Summary of Survey Findings

### The Dimensions of Recovery

The ROSI was found to measure 6 central dimensions of recovery:

1. *Staff and Treatment Satisfaction*
2. Consumers' perceived *Independence*
3. *Access to services*
4. *Invalidated Personhood* (e.g., consumers feel that they are not understood by staff, and their basic rights are not upheld)
5. Consumers' perceived *Support*
6. Consumers' perceived sense of *Encouragement* from others

While there was considerable variation on these six dimensions of recovery, there were only minor differences in average scale scores on these dimensions between consumers receiving services from MHD and non-MHD providers. Therefore, the discussion to follow will refer to both groups combined unless otherwise stated.

**Staff and Treatment Satisfaction.** In the area of *Staff and Treatment Satisfaction*, 70 percent of the respondents indicated that they were always or almost always satisfied with the services they received from their mental health provider. Examples of items from the *Staff and Treatment Satisfaction* scale include "Staff listens carefully to what I say" and "Mental health staff helps me build on my strengths." No significant differences were observed when comparisons were made between females and males, minorities and non-minorities, or provider type (i.e. mental health versus non-mental health providers).

**Independence.** In the *Independence* category, less than half (45 percent) of the respondents agreed or strongly agreed that mental health services helped them get basic resources such as employment, housing, and education. Items comprising this scale include “Services help me develop the skills I need” and “Mental health services helped me get housing in a place I feel safe.” Compared with respondents who received services from mental health providers, respondents who received services from non-mental health providers felt their services were less likely to help them get basic resources. No significant differences were noted for gender or minority status.

**Access.** In the category of *Access* (Figure 13), 70 percent of the respondents agreed or strongly agreed that they had access to services. Items in this scale include “I (can) get the services I need when I need them” and “I can see a therapist when I need to.” Almost two-thirds (63 percent) of the respondents indicated that they can always, almost always, or often see a therapist when they need to; 13 percent can see them sometimes; 24 percent say that they can never or rarely see their therapist when needed. No significant differences were noted for gender, minority status, or agency type.

**Invalidated Personhood.** Sixty percent of the respondents disagreed or strongly disagreed with the *Invalidated Personhood* category. Items comprising this scale include “The mental health staff ignores my physical health” and “Staff does not understand my experience as a person with mental health problems.” Respondents receiving services from non-MHD providers reported feeling more invalidated than respondents receiving services from MHD agencies. Likewise, non-minorities reported feeling less validated than minority participants. No differences were noted on this scale for gender.

**Supports.** In the category of *Supports*, 55 percent of the respondents felt supported often, almost always, or always by the mental health services they received. 22 percent felt supported sometimes, and 23 percent rarely or never felt supported. Items from this scale include “I have information or guidance to get the services and support I need, both inside and outside my mental health agency” and “My family gets the education and supports they need to be helpful to me.” Male respondents perceived more support than female respondents. No significant differences were observed for minority status or agency type.

**Encouragement.** In the category of *Encouragement*, 81 percent agreed or strongly agreed that they were encouraged by the mental health services they received. Examples of items from the Encouragement scale include “I am encouraged to use consumer-run programs (for example: support groups, drop-in centers, etc.)” and “There is at least one person who believes in me.” Male respondents were more likely to report feeling encouraged than were female respondents. No significant differences were reported for minority status or agency type.

## Stigma

For the *Discrimination Experience* scale, over half of the respondents (51 percent) felt stigmatized due to their mental illness. Items from this scale include “Others think I can’t achieve much in life because I have a mental illness” and “People discriminate against me because I have a mental illness.” No significant differences were noted for gender, minority status, or provider type.

## Open-ended Questions

As noted above, seven open-ended questions were offered to consumers to allow them to express in their own words experiences and opinions that would reflect upon the four major needs assessment questions of the Transformation project. Questions include what they liked most and least about the services they received, what they think is working well and not working well in the mental health system, what things could be done to make their life better, and what the ideal mental health system would look like to them.

Open-ended responses were separated out by those with higher scores on the ROSI from those with lower scores on the ROSI. This was done to compare the concerns and opinions of persons who perceive the system as being recovery-oriented with persons who do not perceive the system as being recovery oriented. The responses described below represent all the responses that were made for each question and corresponding percentages represent the proportion of people in each group who mentioned that category.

***What two things do you like most about the mental health services you received?***

The most common response to this question was “Staff.” Staff was mentioned by 46 percent of the participants who perceive the system as being recovery oriented and by 30 percent of the persons who perceive the system as not being recovery oriented. “(The staff’s) attitude when you first go in to see them... (they) seem to understand” is a typical response.

***What about the mental health system in your opinion is working well?***

The highest percentage of respondents did not comment on this question when asked. For respondents who believe the system is recovery oriented, “Service Availability” (25 percent) was the most common response. Twenty-nine percent (29 percent) of the participants who believe the service system is not recovery oriented made a negative comment when asked this question. “I like the line is open so you can talk anytime of the night” represents a typical response.

***What two things do you like the least about the mental health services you received?***

The most common response to this item was “Staffing/Appointment” issues. For those with a non-recovery orientation to the system, “Lack of Services/Termination” of services was the second most common response (35 percent). Nineteen percent of persons who believe the system is recovery oriented did not comment on this issue. A typical response was, “I had a lot of therapists that would constantly be changed.”

***What about the mental health system in your opinion is NOT working well?***

“Lack of Funding” for mental health services was the most common response to this question. “Lack of Therapists/Staff” was the second most common response (25 percent) of people who believe the system is not recovery oriented. “Not enough therapists, too many patients” is a typical response.

***If you were giving advice to the mental health decision-makers in Washington State, what two things would you tell them that they or staff could do to make your life better?***

Improving “Access to Programs/Better Treatment” was the most common response to this question for both groups. The second most frequent response was “Staffing issues,” which includes references to lower caseloads and more money for staff. A typical response was “More funding or ways to help others afford services and meds for those who want to make their life better”

***What would the ideal mental health system look like to you?***

“Better Treatment” was the most common response to this question for both groups. “More treatment for people with drugs and alcohol (issues), and better housing, more money, and more extensive services” was a typical response.

***If the mental health system changed, how would you know it is moving in a positive direction?***

“Greater Access to Services” was the most common response to this question. A typical response was “By the number of people getting treatment and showing positive results.”

## The Survey and Respondents

### Key Questions

To answer the questions identified in the previous section, a telephone survey was developed that included demographic (e.g., gender), open-ended (e.g., “What would the ideal mental health system look like to you?”) and close-ended questions (e.g., “Mental health services helped me get or keep employment.”). Close-ended questions were taken from the Recovery Oriented System Indicators (ROSI) measure and the Internalized Stigma of Mental Illness (ISMI) Scale. Open-ended questions were developed collaboratively by the Evaluation Design Workgroup and were designed to answer the four major needs assessment questions listed above. Demographic questions included employment information, marital status, living situation, age, race, gender, and whether the respondent was currently receiving Medicaid or Medicare health insurance.

Survey data were collected using the Computer Assisted Telephone Interview (CATI) system. The CATI system integrates a questionnaire, databases, and a network of linked computers to allow interviewers to obtain information by telephone. Consistent with the intention of the Transformation Grant, most of the interviewers were themselves consumers of mental health services.<sup>1</sup> Hiring mental health consumers to administer the surveys proved to be a successful strategy. Not only were the interviewers sensitive to the needs and perspectives of the respondents they were interviewing, they also understood the importance of client confidentiality and data integrity. The interviewers did not divulge their status as consumers of mental health services during interviews.

### Survey Participants

The decision to sample those receiving mental health services from both state mental health providers and separately from DSHS service providers that are not mental health providers was made by the Transformation Workgroup Evaluation Committee. The targeted number was 1500 from each of the two populations. Based upon past surveys we anticipated completing @ .33, resulting in @500 completions from each population.

The State Mental Health Division (MHD) produced the sample frame (N = 63,687) for the mental health providers. The data were taken from the MHD MIS data system. Consumers 18 and older that received State funded mental health services from June 1, 2005 to November 30, 2005 are the targeted population. A simple random sample of 1500 was then selected from the sample frame.

The sample for consumers receiving mental health services from non-mental health providers was obtained from The Washington State Research and Data Analysis Division (RDA). The sample included adults with DSHS medical coverage identified through medical claims as having an ICD-9-CM mental illness diagnosis in their medical claims in the 6-month period and not receiving services funded through the Mental Health Division.

The sample frame included 23,427 persons. A simple random sample of 1500 was selected from the sample frame. A simple random sample was drawn from the ACES Barcode Data system.

This survey was conducted between March and June 2006. **633** consumers participated in the survey, yielding a completion rate of 21 percent of the total drawn sample. **384** (26 percent) of the participants received mental health services from publicly funded mental health service providers (The Mental Health Provider Group) and **249** (17 percent) participants received mental health services from other providers (The Non-mental Health Provider Group). The last CATI disposition is presented in Table 1.

<sup>1</sup> Interviewers came from three sources: 14 consumers (Rose house and TACID), 4 non-consumer/non-student, and 3 work-study students, for a total of 21. Five were returning. All went through training. New interviewers (16) received two days of training. Several received additional training according to their needs.

TABLE 1.

Last CATI Disposition*	MENTAL HEALTH		NON-MENTAL HEALTH	
	Number	Percent	Number	Percent
1. Disconnect	223	14.9	247	16.5
2. Wrong Number	316	21.1	341	22.7
3. No Answer	25	1.7	32	2.1
4. Answering Machine	26	1.7	19	1.3
5. Busy	9	.6	4	.3
6. Language Barrier	39	2.6	52	3.5
7. Already Responded	7	.5	3	.2
8. Unavailable	104	6.9	129	8.6
9. Hard Refusal	173	11.5	130	8.7
11. Callback/Not at home	1	.1	4	.3
13. Mid-Terminate	10	.7	7	.5
14. Complete	384	25.6	249	16.6
15. No Mental Health Services Received	31	2.1	122	8.1
16. Deceased	17	1.1	18	1.2
17. Mail Survey	15	1.0	10	.7
18. Left Message with Friend or Relative	45	3.0	42	2.8
19. No Longer at this Number	75	5.0	90	6.0
<b>TOTAL</b>	<b>1,500</b>	<b>100.0</b>	<b>1,500</b>	<b>100.0</b>

\*Numbers above represent the codes that the software uses to identify dispositions. Dispositions 10 and 12 did not come up in the survey, thus do not appear.

## Representativeness

The goal of collecting survey information is to be able to “generalize” the findings to the larger population of interest. To do this, a comparison is made to determine whether the characteristics of the respondent sample (i.e., those who completed the survey) is similar to that of the overall sample – and hence, the consumer population in general. Ideally, the characteristics of the survey participants should match the characteristics of all the persons in the drawn, or total sample. This process is known as determining the participant samples’ “representativeness.” An analysis of the participant samples’ representativeness is presented in Figures 1, 2, and 3.

FIGURE 1.

**Age** (years)

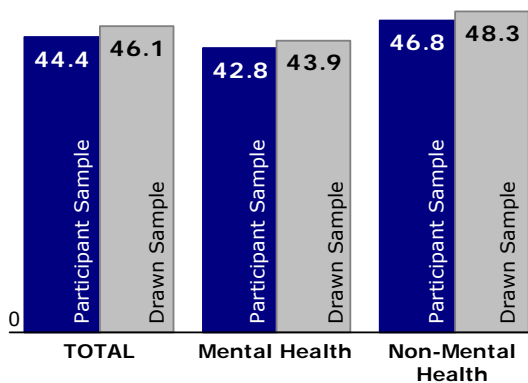
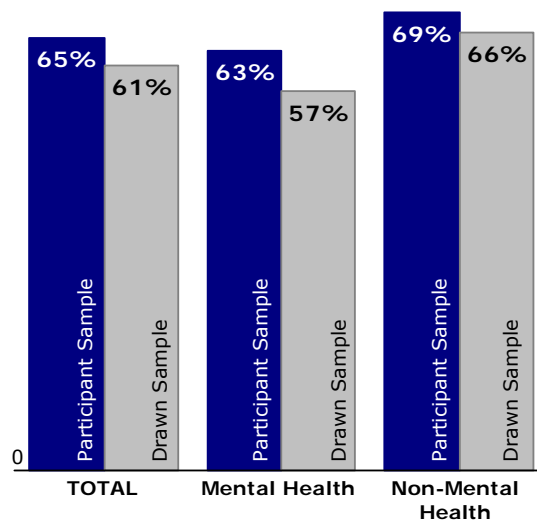


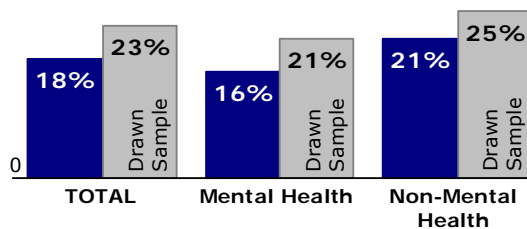
Figure 1 shows that those participating in the survey are younger than those in the drawn sample. This is the case for the total, mental health (MH), and non-mental health (Non-MH) groups. This is typical of survey data in that those that are younger are more likely to be able to participate in the survey; those that are older are more likely to suffer from dementia or other disorder that limits their participation. It should also be noted that the average age of those in the non-mental health group is approximately four years older on average than those in the mental health group.

FIGURE 2.

**Gender** (Percent Female)

In Figure 2, the total percentage of women who participated in the survey (65 percent) is slightly higher than the total percentage of women in the drawn sample (61 percent). Likewise, the percentage of women from the mental health group who participated is higher (63 percent) than those in the drawn sample (57 percent). The percentage of women in the non-MH group who participated is also higher (69 percent) than in the drawn sample (66 percent). The percentage of women surveyed is slightly over-represented from the drawn sample. This is typical of surveys as women are more likely to be found at home during calls than are men.

FIGURE 3.

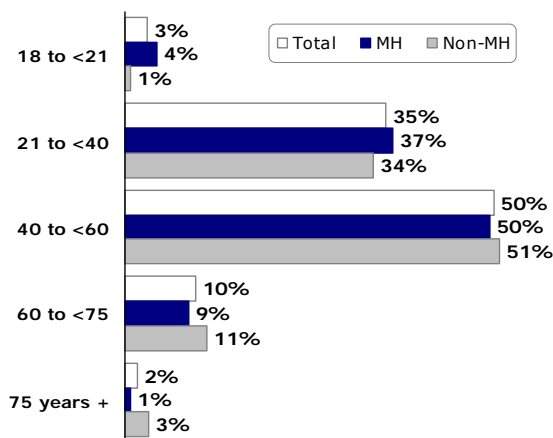
**Minority Status** (Percent Minority)

The total percentage of survey participants who identified themselves as belonging to a minority group is lower than that found in the drawn sample (18 percent vs. 23 percent).

## Demographics of the Respondents

Demographic items from the survey include questions that asked about the participant's age, race or ethnicity, employment status, and other life circumstances.

FIGURE 4.

**Age Category** (Percent Respondent)

Those persons eligible to be surveyed were 18 years or older. Figure 4 shows that half of the participants were between the ages of 40 and 60 years old, followed by people between the ages of 21 and 40. The fewest participants were either over the age of 75 years or under the age of 21 years. Fourteen percent of those in the non-mental health agency group were 60 and older compared to 9 percent in the Mental Health Agency group.

FIGURE 5.

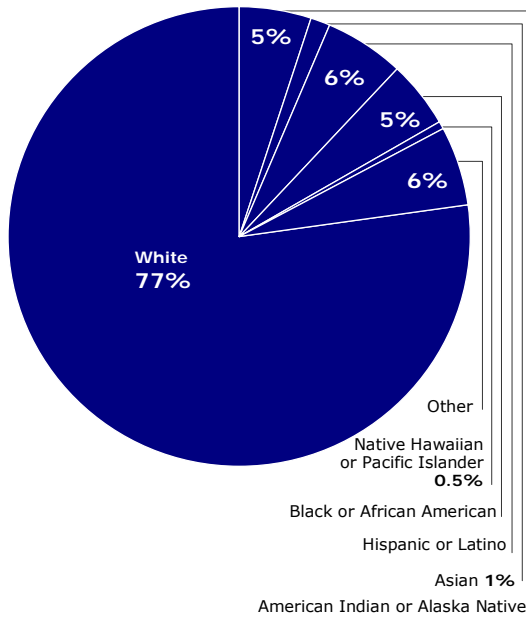
**Race/Ethnicity (TOTAL)**

Figure 5 shows that approximately three quarters (77.2 percent) of the participants indicated that their race or ethnicity was White. Participants who identified themselves as "Other," (5.6 percent) or who said they were Black or African American (5.6 percent) made up the next largest categories, followed by American Indian or Alaskan Native (5.1 percent), Hispanic or Latinos (4.7 percent), and Asian (1.3 percent). Less than one percent of the participants said they were Native Hawaiian or Pacific Islanders.

The proportion of Hispanics is much lower in the Mental health Agencies group than the Non-mental health agencies group. The percentage of Hispanics should be at 6 percent not 3.7 percent as indicated in Figure 6.

The proportion of American Indians/Alaskan Natives was twice as large in the Non-mental health agencies group (7.4 percent) compared with the Mental health agencies group (3.7 percent).

FIGURE 6.

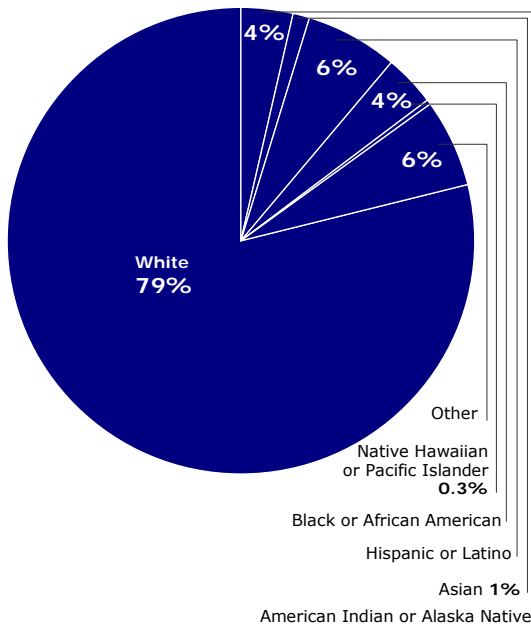
**Race/Ethnicity (Mental Health Agencies)**

FIGURE 7.

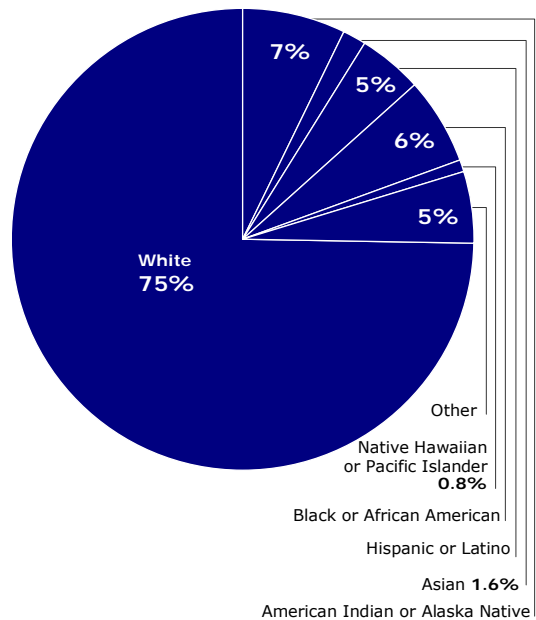
**Race/Ethnicity (Non-Mental Health Agencies)**

FIGURE 8.

### Employment Status (TOTAL)

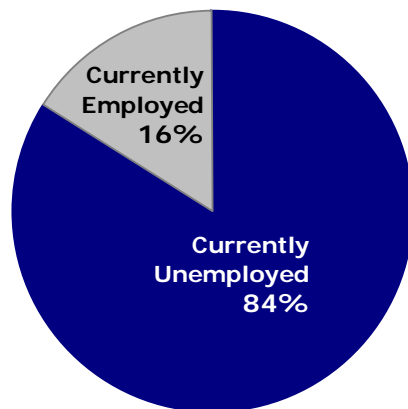


Figure 8 shows that most of the people who completed the survey from either mental health or non-mental health agencies were not currently employed. A larger number were employed from mental health agencies (18 percent) than were employed from non-mental health agencies (11 percent), Figures 9 and 10.

FIGURE 9.

### Employment Status (Mental Health Agencies)

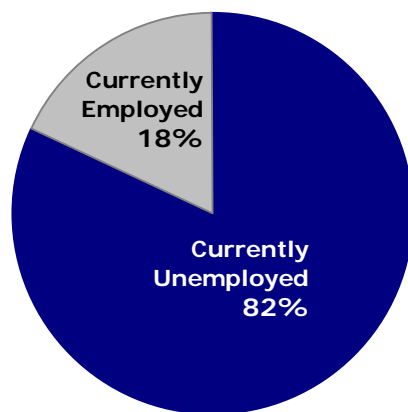
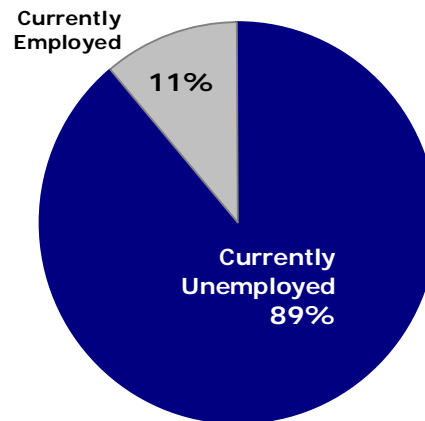


FIGURE 10.

### Employment Status (Non-Mental Health Agencies)



## The Recovery Oriented System Indicators (ROSI) Measure

The ROSI is a 42-item self-report questionnaire designed to assess what helps and what hinders mental health recovery at the systems-level. Ideally, the ROSI is a "report card" that can be used across time to measure changes, both positive and negative, within a mental health system.

The ROSI is a recently developed instrument that has little technical information. One objective in this first survey is to determine whether the scale is multidimensional and, if so, what are the dimensions, or components.

Onken (2004) identified eight components resulting from a factor analysis done on the 42 item consumer survey items. The eight components include:

1. Person-Centered Decision Making and Choice
2. Invalidated Personhood
3. Self-Care and Wellness
4. Basic Life Resources
5. Meaningful Activities and Roles
6. Peer Advocacy
7. Staff Treatment Knowledge
8. Access

Onken (2004) reported nothing on what type of factor analysis was used, the sample size, factor loadings or other technical information. Therefore, we conducted our own factor analysis. Appendix 1 and 2 show the loadings that we obtained from our factor analysis.<sup>2</sup> Appendix 1 shows the item loadings that we obtained matched to the item components reported by Onken (2004). While there are some common loadings, generally our item loadings do not match well with components reported by Onken (2004). Therefore, we constructed our own scales based upon the item loadings that we obtained. The components and item loadings appear in Appendix 2. The components obtained were then tested for reliability using Cronbach's Alpha, a common measure of internal consistency of scaled items. We consider alphas of .7 or better to be a reliable scale. The components, along with their corresponding Alpha's appear in the Table below.

TABLE 2.

Scale and Reliability Alphas	Reliability ALPHA
<b>Staff and Treatment Satisfaction Scale</b>  My right to refuse treatment is respected. (Always...Never) Staff give me complete information in words I understand before I consent to treatment or medication. (Always...Never) Staff listen carefully to what I say. (Always...Never) Mental health staff support my self-care or wellness. (Always...Never) Staff see me as an equal partner in my treatment program. (Always...Never) Staff encourage me to do things that are meaningful to me. (Always...Never) Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual orientation). (Always...Never) Staff believe that I can grow, change and recover. (Always...Never) Mental health staff help me build on my strengths. (Always...Never) I have a say in what happens to me when I am in crisis. (Always...Never) Staff stood up for me to get the services and resources I needed. (Always...Never) My treatment plan goals are stated in my own words. (Always...Never) The doctor worked with me to get on medications that were most helpful for me. (Always...Never) Mental health staff interfere with my personal relationships. (Never...Always) I am treated as a psychiatric label rather than as a person. (Never...Always)	<b>.931</b>
<b>Independence Scale</b>  I have enough income to live on. (Strongly Agree...Strongly Disagree) Mental health services helped me get or keep employment. (Always...Never) Services help me develop the skills I need. (Strongly Agree...Strongly Disagree) I have a chance to advance my education if I want to. (Always...Never) Mental health services helped me get housing in a place I feel safe. (Strongly Agree...Strongly Disagree) There was a consumer peer advocate to turn to when I needed one. (Always...Never)	<b>.768</b>

<sup>2</sup> Our factor analysis was done using principle components extraction with Varimax rotation (N = 480).

<b>Access Scale</b>	<b>.692</b>
I do not have enough good service options to choose from. (Strongly Disagree...Strongly Agree) I do not have the support I need to function in the roles I want in my community. (Strongly Disagree...Strongly Agree) I cannot get the services I need when I need them. (Strongly Disagree...Strongly Agree) I can see a therapist when I need to. (Always...Never) I have reliable transportation to get where I need to go. (Always...Never)	
<b>Invalidated Personhood</b>	<b>.699</b>
Mental health services led me to be more dependent, not independent. (Strongly Disagree...Strongly Agree) Staff do not understand my experience as a person with mental health problems. (Strongly Disagree...Strongly Agree) The mental health staff ignore my physical health. (Strongly Disagree...Strongly Agree) I lack the information or resources I need to uphold my client rights and basic human rights. (Strongly Disagree...Strongly Agree)	
<b>Supports Scale</b>	<b>.652</b>
There are consumers working as paid employees in the mental health agency (service agency) where I receive services. (Always...Never) I have information or guidance to get the services and support I need, both inside and outside my mental health agency. (Always...Never) My family gets the education or supports they need to be helpful to me. (Always...Never)	
<b>Encouragement Scale</b>	<b>.619</b>
There is at least one person who believes in me. (Strongly Agree...Strongly Disagree) I am encouraged to use consumer-run programs (for example: support groups, drop-in centers, etc.). (Strongly Agree...Strongly Disagree) Staff respect me as a whole person. (Strongly Agree...Strongly Disagree) Mental health services helped me get medical benefits that meet my needs. (Strongly Agree...Strongly Disagree)	

### Scales by Agency Type

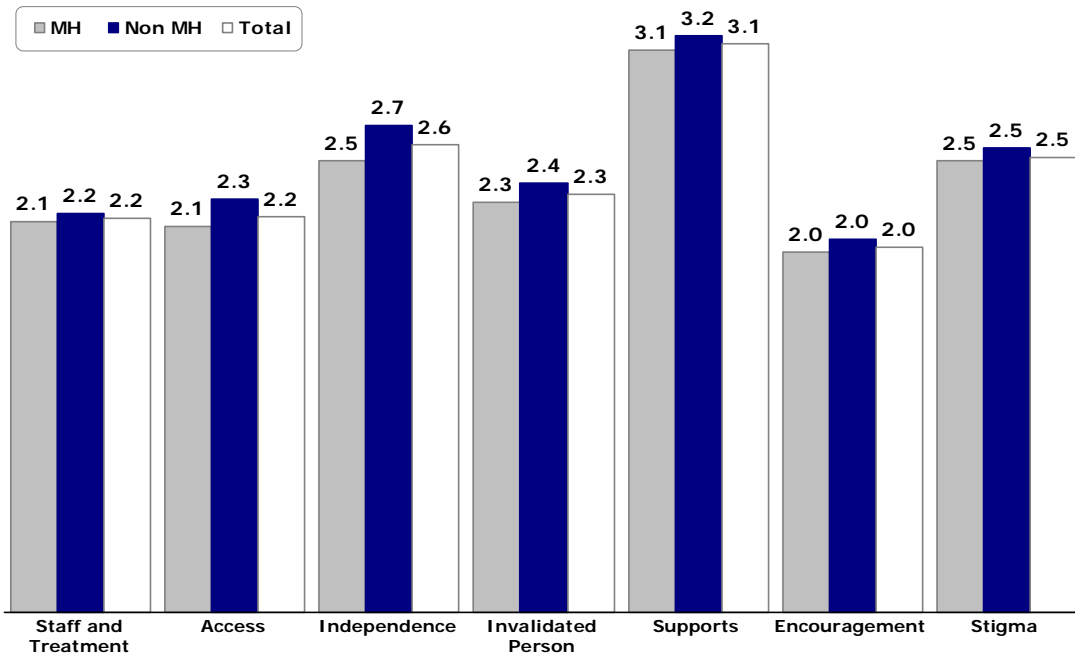
The following figures (11 through 17) show scale scores of respondents by agency type.<sup>3</sup> Figure 11 shows the average scores for each of the scales by agency and for the agencies combined. There is little difference in scale score averages between the two agency types.

In Figures 12 through 17 the average scale scores were collapsed into categories so that the approximate percentage of scores falling into each of the categories can be observed. There are two response categories for the scales (Strongly agree (1- 1.49), Agree (1.5-2.49), Disagree (2.5-3.49), Strongly disagree 3.5-4.0) and (Always (1- 1.49), Almost always (1.5-2.49), Often (2.5-3.49), Sometimes (3.5-4.49), Rarely (4.5-5.49), Never 5.5-6.0)).

For the **ROSI scales**, *positive scores for scales are the lowest scores; higher scores indicate dissatisfaction with the items.*

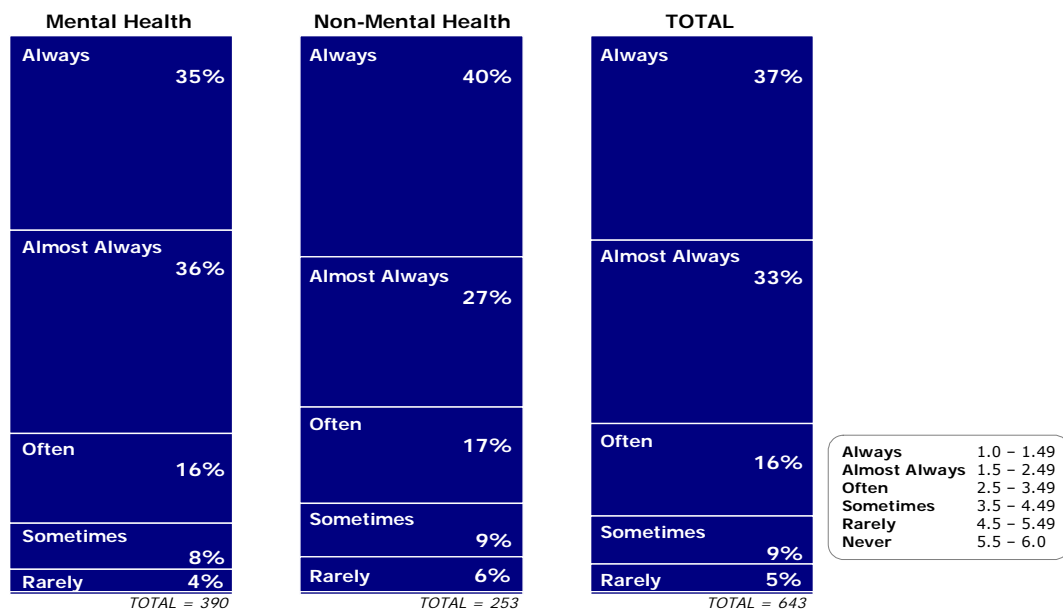
<sup>3</sup> Scale items were recoded to calculate same direction scale scores and to equalize number of response categories.

FIGURE 11.

**Scale Scores (Mean) by Agency Type****Staff and Treatment Satisfaction**

In the area of *Staff and Treatment Satisfaction* (Figure 12) 70 percent of the respondents indicated that they were Always or Almost always satisfied with the services they received from their mental health provider. Less than 6 percent said that they were Rarely or Never satisfied with the staff and treatment they received. No significant differences were observed when comparisons were made between females and males, minorities and non-minorities, and provider type (i.e. mental health versus non-mental health providers).

FIGURE 12.

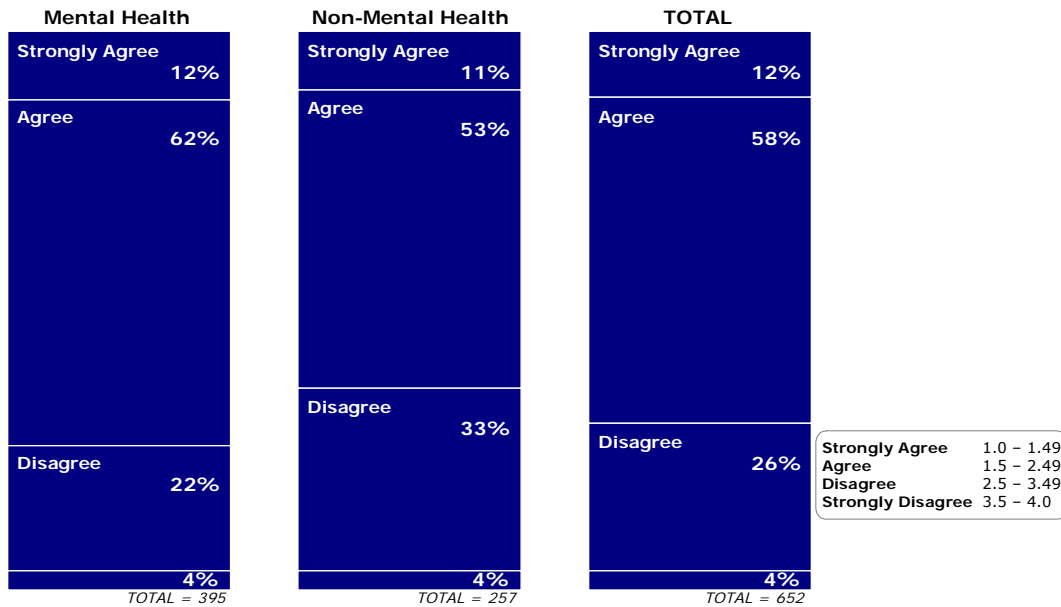
**Staff and Treatment Satisfaction by Agency Type**

## Access to Services

In the category of *Access* (Figure 13), 70 percent of the respondents Agreed or Strongly agreed that there had access to services. Items in this scale include “I (can) get the services I need when I need them” and “I can see a therapist when I need to.” Almost two-thirds (63 percent) of the respondents indicated that they can Always, Almost always, or Often see a therapist when they need to; 13 percent can see them Sometimes; 24 percent say that they can Never or Rarely see their therapist when needed. No significant differences were noted for gender, minority status, or agency type.

FIGURE 13.

### Access by Agency Type

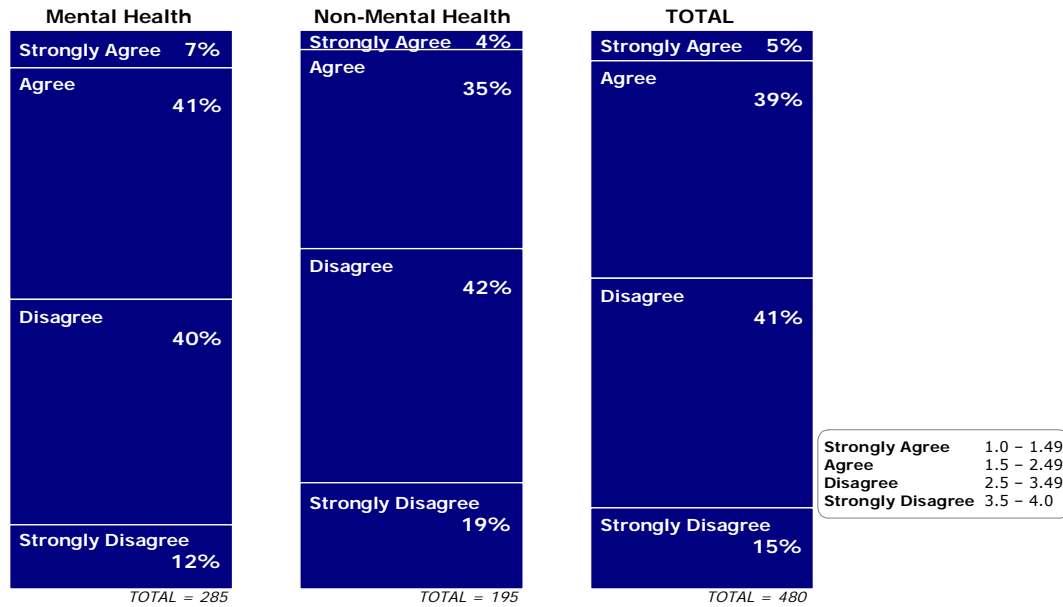


## Perceived Independence

In the *Independence* category, less than half (44 percent) of the respondents Agreed or Strongly agreed that mental health services helped them get basic resources such as employment and housing. Items comprising this scale include “Mental health services helped me get housing in a place I feel safe,” and “Mental health services helped me get or keep employment.” Most respondents (56 percent) reported that they have *Never* been helped by mental health services to get or keep employment (table not shown).

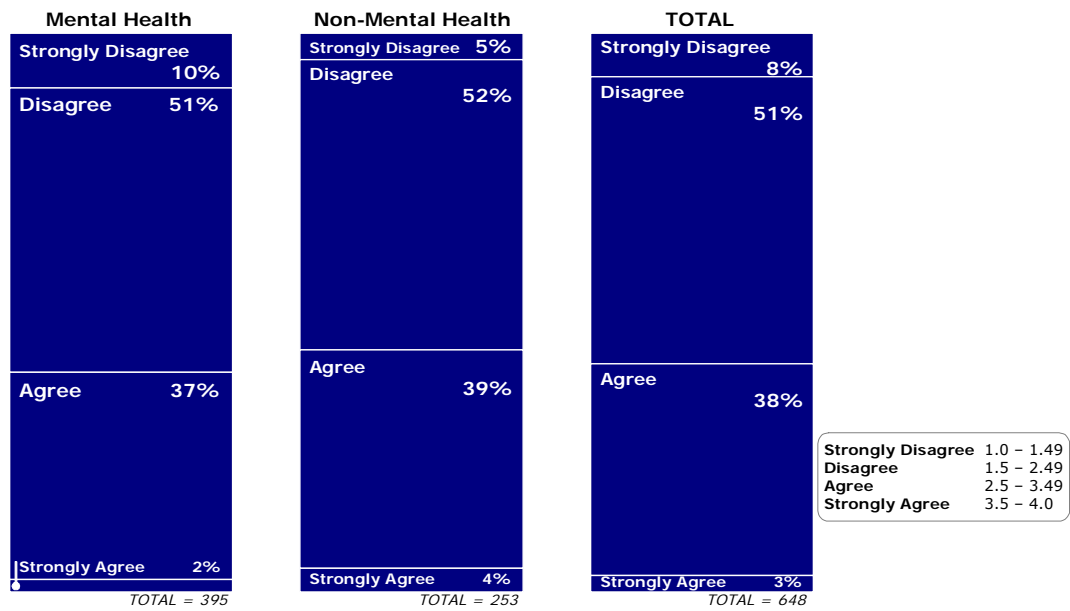
Compared with respondents who received services from MHD providers, respondents who received services from non-MHD providers felt their services were less likely to help them get basic resources (51 percent vs 62 percent). No significant differences were noted for gender or minority status.

FIGURE 14.

**Independence by Agency Type****Invalidated Personhood**

Fifty-nine percent of the respondents Disagreed or Strongly disagreed with the *Invalidated Personhood* category. Items comprising this scale include “The mental health staff ignore my physical health” and “Staff do not understand my experience as a person with mental health problems.” Respondents receiving services from non-MHD providers reported feeling invalidated more than respondents receiving services from MHD agencies. Likewise, non-minorities reported feeling validated less than minority participants. No differences were noted on this scale for gender.

FIGURE 15.

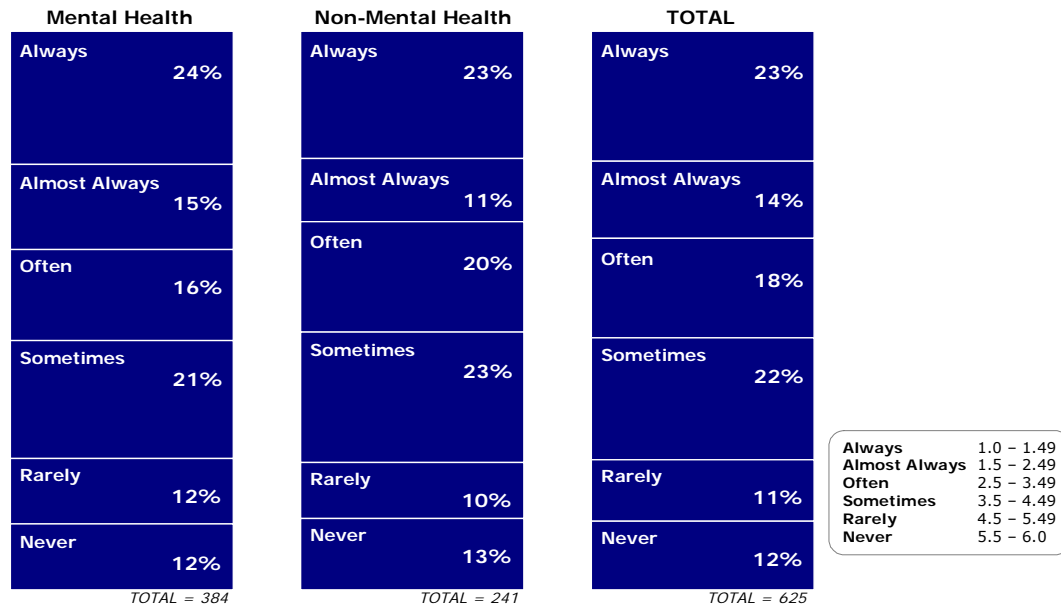
**Invalidated Personhood by Agency Type**

## Support

In the category of *Supports*, 55 percent of the respondents felt supported Often, Almost always, or Always by the mental health services they received. 22 percent felt supported Sometimes, and 23 percent Rarely or ever felt supported. Items from this scale include “I have information or guidance to get the services and support I need, both inside and outside my mental health agency” and “My family gets the education and supports they need to be helpful to me.” Male respondents perceived more support than female respondents. No significant differences were observed for minority status or agency type.

FIGURE 16.

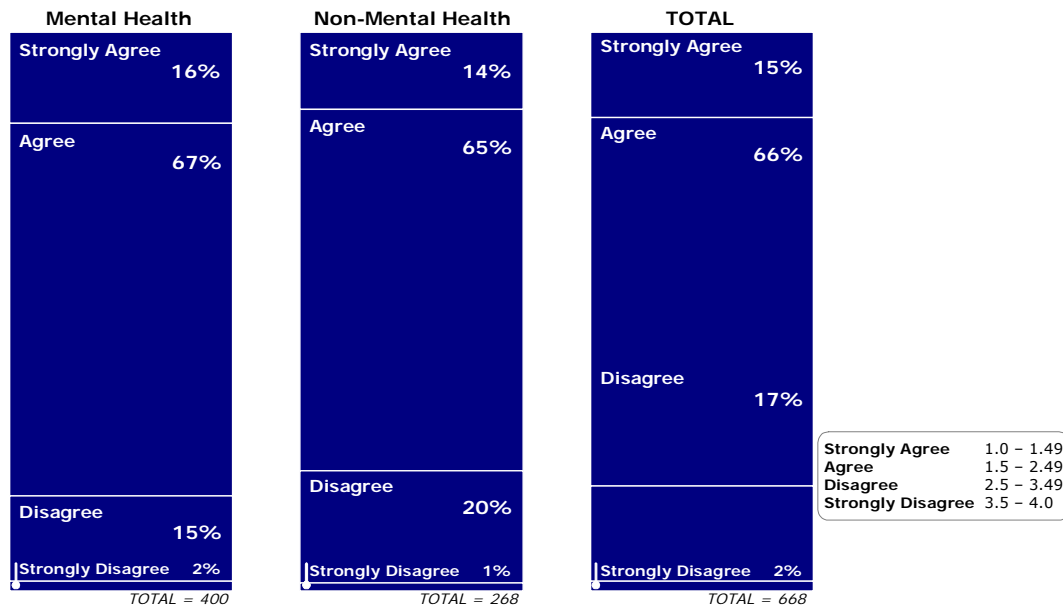
### Supports by Agency Type



## Encouragement

In the category of *Encouragement*, 81 percent Agreed or Strongly agreed that they were encouraged by the mental health services they received. Examples of items from the Encouragement scale include “I am encouraged to use consumer-run programs (for example: support groups, drop-in centers, etc.)” and “There is at least one person who believes in me.” Male respondents were more likely to report feeling encouraged than were female respondents. No significant differences were reported for minority status or agency type.

FIGURE 17.

**Encouragement by Agency Type****The Discrimination Experience Subscale**

The Discrimination Experience Subscale is part of the Internalized Stigma of Mental Illness (ISMI) Scale and was designed to assess the respondents' perception of the way they are treated by other people (Ritsher, Otilingam, and Grajales, 2003). The scale shows a high degree of reliability as measured by Cronbach's Alpha.

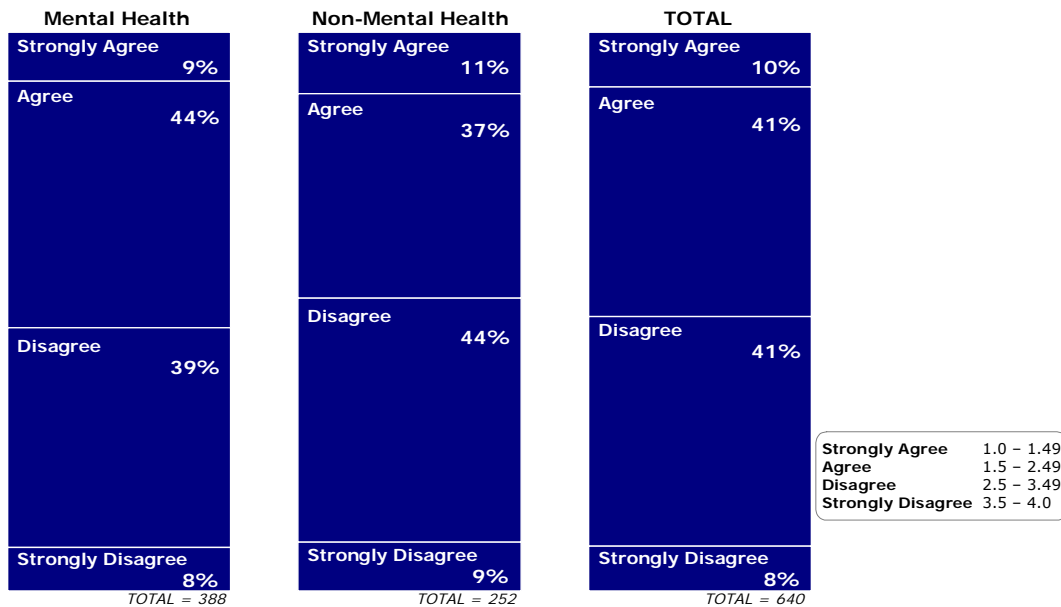
TABLE 3.

Discrimination Experience Scale	Reliability ALPHA
<b>Discrimination Experience Scale</b>  People discriminate against me because I have a mental illness. (Strongly Agree...Strongly Disagree) Others think I can't achieve much in life because I have a mental illness. (Strongly Agree...Strongly Disagree) People ignore me or take me less seriously just because I have a mental illness. (Strongly Agree...Strongly Disagree) People often patronize me, or treat me like a child, just because I have a mental illness. (Strongly Agree...Strongly Disagree) Nobody would be interested in getting close to me because I have a mental illness. (Strongly Agree...Strongly Disagree)	<b>.852</b>

Figures 18, 19, and 20 show the stigma responses by agency type, minority status, and gender. For the **stigma scale**, lower scores indicated a higher degree of perceived stigma.

For the *Discrimination Experience* scale, over half of the respondents (51 percent) felt stigmatized due to their mental illness. No significant differences were noted for gender, minority status, or provider type.

FIGURE 18.

**Stigma by Agency Type****Open-ended Questions**

In the Transformation Grant survey, seven of the questions gave participants the opportunity to express their responses in their own words. These seven questions were posed in such a way as to draw out from the respondents how specific problems and solutions are related to the four major needs assessment questions of the Transformation Grant. For example, one question asked participants, “What is working well within the mental health system?” Another asked participants to envision a more positive future: “What would the ideal mental health system look like to you?”

After the researchers reviewed answers to each question, the statements were then divided into broad categories of responses. Two trained and experienced interviewers assigned each response to a corresponding category. The inter-rater reliability was assessed for each question.<sup>4</sup>

For each question, responses were broken out by recovery/non-recovery orientation on the ROSI. The seven ROSI scales identified above were combined into one scale. Respondents who scored in the upper 26<sup>th</sup> percentile (mostly disagree and strongly disagree; mean > 2.75) on the ROSI were categorized as believing the mental health system has a non-recovery orientation (**the ROSI\_NR group**) whereas respondents scoring in the lower 74<sup>th</sup> percent (mostly agree and strongly agree; mean < 2.75) were categorized as believing the service system has a recovery orientation (**the ROSI\_R group**).

<sup>4</sup> A 10 percent random sample was conducted on all the open-ended questions for the May intermediate report (N=480) and on four of the seven questions for the final report (N=633). Inter-rater reliability was consistently high (>90 percent), with an average error rate of 7.9 percent.

### QUESTION 1: What two things do you like the most about the mental health services you received?

**Staff**—Includes references to the counseling and non-counseling members of the agency's team

**Management and Access to Medications**—Includes any reference to medications and/or prescriptions

**Availability of Services**—Refers to ease and flexibility of scheduling appointments and convenience of the location of services

**Self-Improvement/Treatment and Results**—Refers to progress made and results of treatment

**Negative Response**—Contains negative responses to a positively-phrased question (such as "I don't like anything about the mental health system")

**Communication**—Includes general comments about listening and caring

**Other**—Includes other responses that don't fall into the categories listed

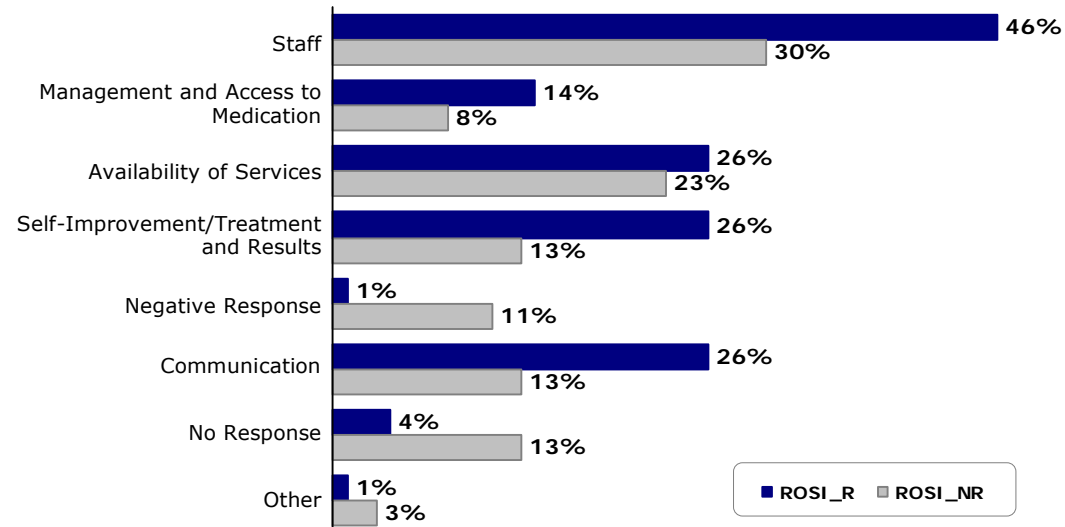
**No Response**—Respondent did not have a response to the question (field either left blank or respondent simply said 'don't know')

**'Nothing'**—Refers to the specific response, 'Nothing.' (As this response can be interpreted in several different ways even as a lack of response, a separate category has been created)

FIGURE 19.

#### Positive comments about services by group

QUESTION: What two things do you like the most about the mental health services you received?



#### ROSI\_R

"I like the fact that they treated me like a real person and there are a lot of options for me."

"I like that if I need to cancel (my appointment) I can get another appointment. My counselor is very helpful with suggestions."

"The expertise and the courtesy."

The most frequent response to the question "What two things do you like the most about the mental health services you received?" was *Staff*.

Respondents who perceived the system as having a non-recovery orientation (i.e., the ROSI\_NR group) were much more likely to *Not Respond* (13%), say "*Nothing*" (9%) or reply with a *Negative Response* (11%) to this question than were respondents who perceived the system as being recovery oriented (i.e., the ROSI\_R group).

#### ROSI\_NR

"My doctor helps me."

"There is nothing I like about the services I received."

"They give me a place to go every day to be around people."

## QUESTION 2: What about the mental health system in your opinion is working well?

**Service Availability/Works well**—Refers to the existence of an identifiable mental health system, as well as general positive comments such as “works well.”

**Access to Medication**—Includes any reference to medications and/or prescriptions

**Staffing**—Includes references to the counseling and non-counseling members of the agency’s team, including praise for staff members

**Support System**—Refers to the ability to receive services for crisis management and treatment

**Negative Response**—Contains negative responses to a positively-phrased question (such as “I don’t like anything about the mental health system”)

**‘Nothing’**—Refers to the specific response, ‘Nothing.’

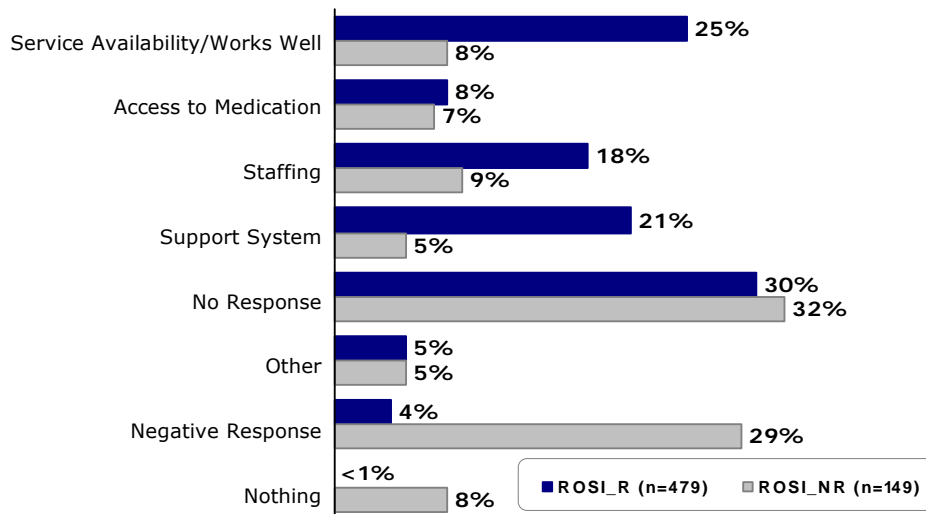
**Other**—Includes other responses that don’t fall into the categories listed

**No Response**—Respondent did not have a response to the question (field either left blank or respondent simply said ‘don’t know’)

FIGURE 20.

### What is working well by group

QUESTION: What about the mental health system in your opinion is working well?



#### ROSI\_R

“I do believe that they are finally beginning to realize that people get better, then they get worse, and then they get better again.”

“Getting help to people who need it.”

“The staff are very helpful and give a lot of information.”

The highest percentage of respondents did not comment on what they thought was working well in the mental health system.

The most common response for participants from the ROSI\_NR group was a Negative Response (29%).

The most common response for participants from the ROSI\_R group was *Service Availability/Works Well* (25%).

#### ROSI\_NR

“It’s not working well.”

“It works for people who are low or no income.”

“The crisis line is all that is working well.”

### QUESTION 3: What two things do you like the LEAST about the mental health services you received?

**Access to Services**—Includes references to difficulty obtaining services, completing paperwork, and financial issues in paying for services

**Staffing/appointments**—Refers to staffing issues (e.g., frequently changing staff) and availability and scheduling of appointments

**Medications/Treatments**—Includes medication and treatment issues for both group therapy and individual therapy

**Lack of services/Termination**—Refers to respondent experiences with qualifying for and/or becoming ineligible for mental health services

**Positive Response**—Contains positive responses to a negatively-phrased question (such as “I like everything about the mental health system”)

**‘Nothing’**—Refers to the specific response, ‘Nothing.’ (As this response can be interpreted in several different ways even as a lack of response, a separate category has been created)

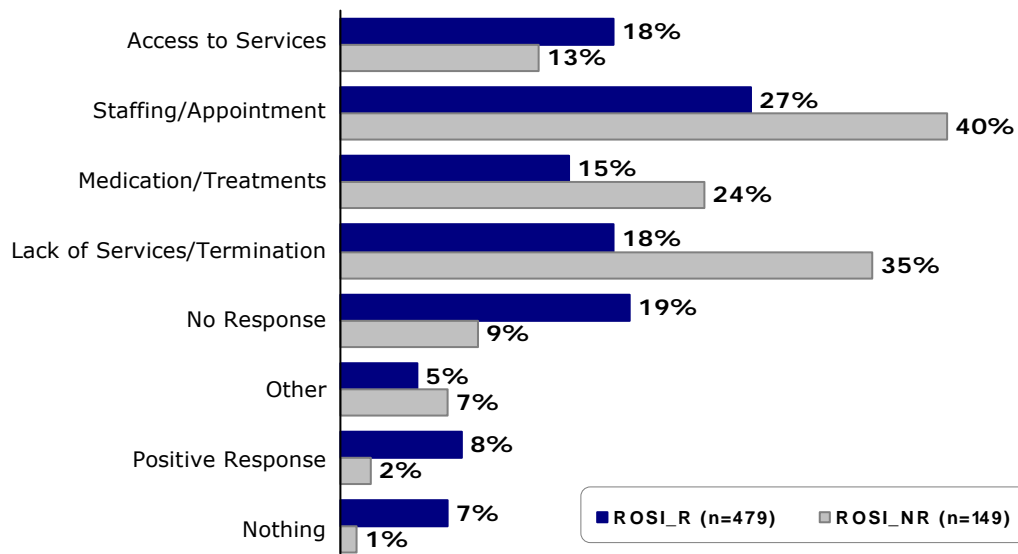
**Other**—Includes other responses that don’t fall into the categories listed

**No Response**—Respondent did not have a response to the question (field either left blank or respondent simply said ‘don’t know’)

FIGURE 21.

#### Negative comments about services by group

QUESTION: What two things do you like the least about the mental health services you received?



#### ROSI\_R

“Not giving prior notice that review is coming up and then being kicked off services and having to go through intake all over again.”

“The first psychiatrist didn’t listen to me. I wasted a year with him. Frustrating.”

“It was hard to get in to see a therapist . . . (I) had to wait six weeks.”

*Staffing/Appointment* issues was the most frequently mentioned response when participants were asked what they liked least about the mental health services they received.

*Lack of services/Termination* (35%) of services was the second most common response from participants in the ROSI\_NR group.

#### ROSI\_NR

“The resources are exhausted, high turnover in doctors, revolving door treatment, never see the same doctor twice.”

“Services are available but not known (about).”

“That they cut me off medicine that was working extremely well . . . They cut me off too soon.”

#### QUESTION 4: What about the mental health system in your opinion is NOT working well?

**Lack of Funding**—Refers to the overall lack of funding available for mental health services, and concerns about health insurance

**No Follow-up/Lack of support**—Includes comments about on-going mental health support and follow-up within the mental health system

**Lack of Therapist**—Concerns about a lack of properly-trained therapeutic staff, and the high turnover of staff

**Medication problems**—Refers to medication issues, including concerns about over-medication and under-medication

**Bureaucratic issues**—Includes references to difficulty accessing services due to large amounts of paperwork required to navigate the mental health system effectively

**Positive Response**—Contains positive responses to a negatively-phrased question (such as “I like everything about the mental health system”)

**‘Nothing’**—Refers to the specific response, ‘Nothing.’ (As this response can be interpreted in several different ways even as a lack of response, a separate category has been created)

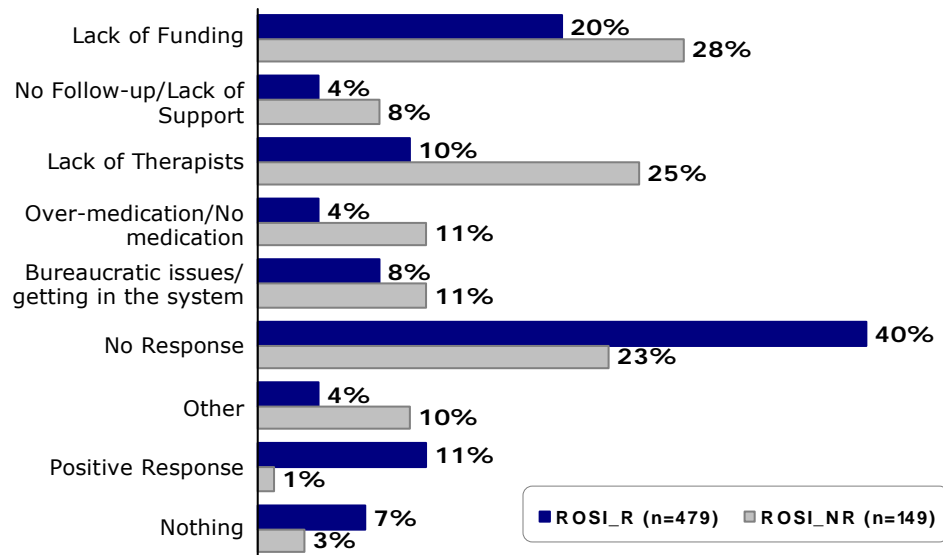
**Other**—Includes other responses that don’t fall into the categories listed

**No Response**—Respondent did not have a response to the question (field either left blank or respondent simply said ‘don’t know’)

FIGURE 22.

#### Negative comments about how the system works by group

QUESTION: What about the mental health system in your opinion is NOT working well?



#### ROSI\_R

“Not enough therapists to (too) many patients.”

“Programs are being cut. Not enough funding. They closed down a crisis center.”

“The distance I have to travel for services.”

*Lack of Funding (20%) was the most common response of respondents for both the ROSI\_NR and ROSI\_R groups.*

*Twenty-five percent of the ROSI\_NR group identified Lack of Therapists as something that was not working well.*

#### ROSI\_NR

“People can’t get medical coupons but can’t afford it ‘out of pocket’.”

“Insufficient access to treatment—I had to go through a lot to get in.”

“I think the lack of therapists . . . it’s hard to get a therapist because they are full and get switch(ed).”

**QUESTION 5: If you were giving advice to the mental health decision-makers in Washington State, what TWO things would you tell them that they or staff could do to make your life better?**

**More money/clinics**—Includes references to allocating more money for mental health programs and staff

**Access to Programs/Better Treatment**—Includes responses regarding improving the availability and quality of mental health treatment, as well as alternative treatments

**Family services**—Refers to comments about improving family support services for mental health consumers and their families

**Transportation/Education/Housing/Employment**—Suggestions about how the mental health system could improve access to personal services for mental health consumers

**Staffing issues**—Includes references to staffing, funding for staff and training, and to lower caseloads within the mental health system

**'Nothing'**—Refers to the specific response, 'Nothing.' (As this response can be interpreted in several different ways even as a lack of response, a separate category has been created)

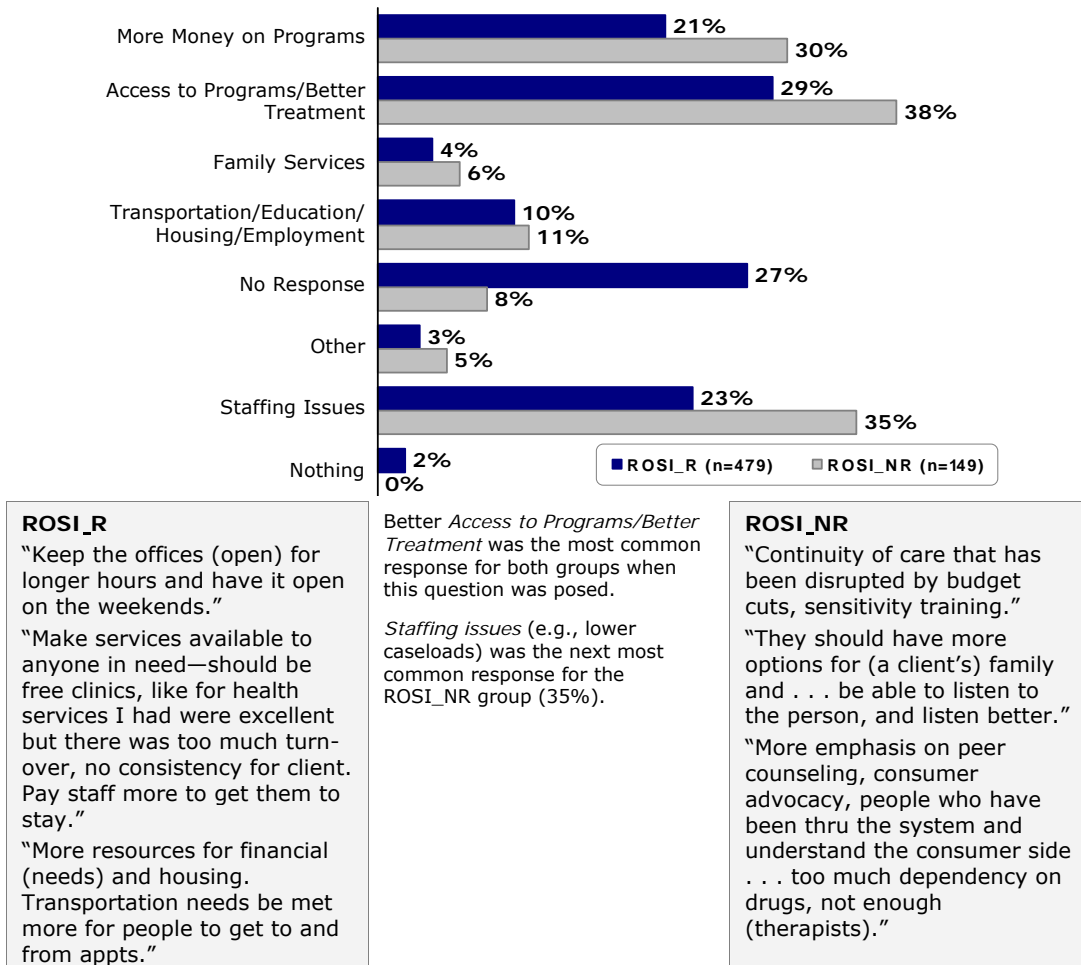
**Other**—Includes other responses that don't fall into the categories listed

**No Response**—Respondent did not have a response to the question (field either left blank or respondent simply said 'don't know')

FIGURE 23.

**Comments about advice to mental health decision-makers by group**

QUESTION: If you were giving advice to the mental health decision-makers in Washington State, what TWO things would you tell them that they or staff could do to make your life better?



## QUESTION 6: What would the ideal mental health system look like to you?

**Accessibility for All**—Includes general comments about the ability for anyone to access mental health services when needed

**Better Staff/Training**—Refers to the need for more staffing with better training

**Better Treatment**—Comments referring to increased availability of treatment programs, as well as better treatment alternatives

**Employment/Other Services**—Suggestions about how the mental health system could improve access to personal services for mental health consumers

**Insurance/Financial**—Refers to increased funding available for mental health services, as well as access to health insurance

**Fine as it is**—Includes comments from respondents who indicated that they felt the mental health system is working fine as it is right now

**Better Communication/Less Stigma**—Includes general comments from respondents who wished for better communication and/or less stigma within the mental health system. Also included comments calling for education about mental illness for the general population.

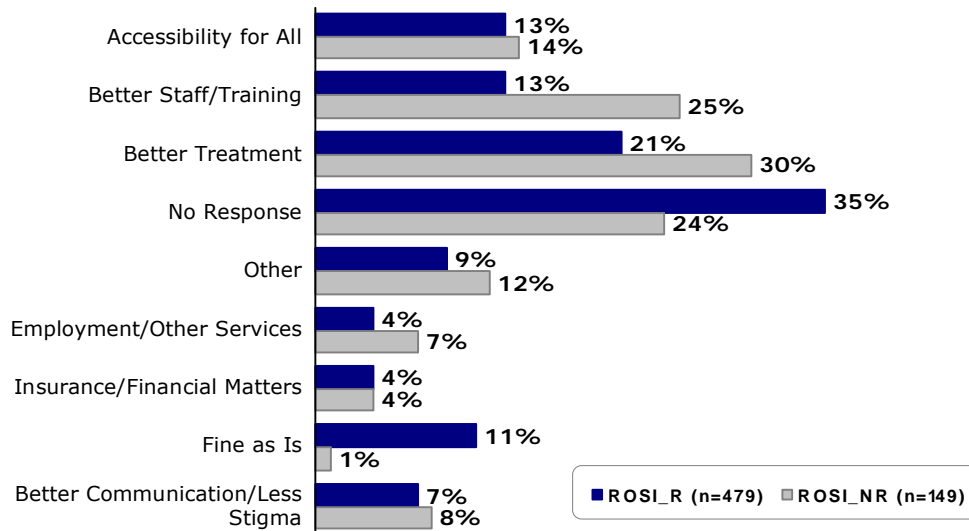
**Other**—Includes other responses that don't fall into the categories listed

**No Response**—Respondent did not have a response to the question (field either left blank or respondent simply said 'don't know')

FIGURE 24.

### Comments about ideal mental health by group

QUESTION: What would the ideal mental health system look like to you?



#### ROSI\_R

"Primarily, it would be cheaper."

"I would like to see mental health care—to be screened—when we are very young. Starting in kindergarten."

"A system where even consumers can work together to provide mental health treatment."

*Better Treatment* (30%) was the most common response from both groups.

*Better Staff/Training* was the second most common response (25%) for the ROSI\_NR group; only 13% of the ROSI\_R group identified this as part of an ideal mental health system.

#### ROSI\_NR

"More treatment for people with drugs and alcohol (issues), and better housing, more money, and more extensive services."

"Available and free."

"You ought to build more hospitals and fewer jails, because lots of the guys in jail should be in a hospital instead."

## QUESTION 7: If the mental health system changed, how would you know it is moving in a positive direction?

**Greater Access to services**—Refers to comments about the ability of more individuals to access services when needed, as well as improved treatment programs.

**Media/word of mouth**—Includes comments about changes would be reported in the media (t.v., newspaper, radio) and by surveys, as well as discussed in conversation within society.

**Less people on streets/jails**—Specific references made to fewer homeless people and fewer people incarcerated.

**General Population Temperament**—Includes comments about how positive changes in the mental health system would be positively connected to changes in behavior and attitude within the general population

**Personal experience**—Refers to comments by a respondent that he or she would directly observe changes in the mental health system

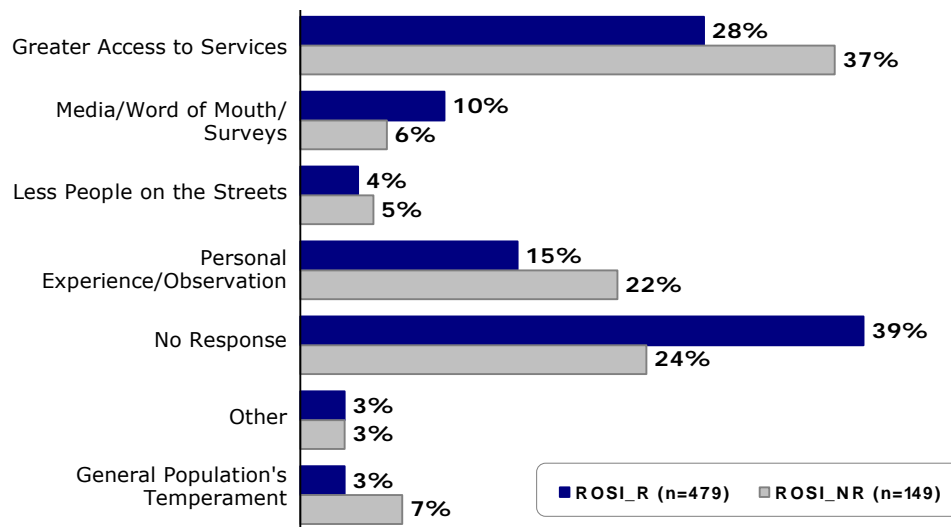
**No Response**—Respondent did not have a response to the question (field either left blank or respondent simply said 'don't know')

**Other**—Includes other responses that don't fall into the categories listed

FIGURE 25.

### Identifying positive changes by group

QUESTION: If the mental health system changed, how would you know it is moving in a positive direction?



#### ROSI\_R

"(I would) hear it in my NAMI groups, groups, news papers."

"By the number of people getting treatment and showing positive results."

"It doesn't take you so long to get in."

"I would see more on tv about it."

For both groups, the most common response was *Greater Access to Services*.

This was followed by "Personal Experience/Observation."

#### ROSI\_NR

"They should listen to people and provide necessary social services."

"There would be more programs that had proper funding."

"Better communication. Attempting to educate the general population about the services available."

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Ritsher, J.B., Otilingam, P.G., and Grajales, M. (2003). Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry Research*, 121, 31-49.

## ATTACHMENT 1: Loadings on Scales Identified in ROSI Report

## Person-Centered Decision Making and Choice

	COMPONENT							
	1	2	3	4	5	6	7	8
q31. Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual).	.681	.050	.010	-.114	-.008	.098	-.139	.071
q18. Staff believe that I can grow, change and recover.	.673	.301	.018	-.235	.054	.036	.004	-.135
q28. Staff give me complete information in words I understand before I consent to treatment or medication.	.735	.015	.074	-.070	.216	.037	-.072	.105
q32. Staff listen carefully to what I say.	.734	.122	.156	-.123	.166	.091	-.064	-.005
q30. Staff stood up for me to get the services and resources I needed.	.601	.205	.232	.065	.320	.254	-.130	.111
q29. Staff encourage me to do things that are meaningful to me.	.687	.280	.125	-.107	.175	.079	-.061	-.015
q21. Staff see me as an equal partner in my treatment program.	.706	.161	.069	-.091	.105	.158	-.261	.027
q17. I have a say in what happens to me when I am in crisis.	.620	.240	.170	.002	-.093	.064	.088	-.055
q38. The doctor worked with me to get on medications that were most helpful for me.	.525	.093	.358	-.015	.051	.068	-.051	-.022
q42. I have information or guidance to get the services and support I need, both inside and outside my mental health agency.	.349	.279	.405	.036	.472	.105	-.205	.003
q20. Staff use pressure, threats, or force in my treatment.	-.457	.037	-.166	.097	.089	-.135	.484	-.042
q14. I lack the information or resources I need to uphold my client rights and basic human rights.	-.096	-.119	-.248	.570	-.096	-.183	.309	-.071
q12. Mental health services helped me get medical benefits that meet my needs.	.188	.311	.288	.185	.218	.394	-.064	.199
q3. There is at least one person who believes in me.	.210	-.024	.141	-.262	-.107	.625	.120	.204
q27. There are consumers working as paid employees in the mental health agency (service agency) where I receive services.	.149	.074	-.018	-.075	.814	.008	.145	-.016
q37. My treatment plan goals are stated in my own words.	.577	.105	.048	-.206	.360	.007	.110	.278

## Invalidated Personhood

q39. I am treated as a psychiatric label rather than as a person.	-.497	-.063	-.066	.298	-.154	.036	.376	-.100
q4. I do not have the support I need to function in the roles I want in my community.	-.107	-.093	-.697	.190	.052	.063	-.004	-.043
q34. Mental health staff interfere with my personal relationships.	-.522	.111	-.186	-.018	-.028	.032	.326	-.063
q7. Staff do not understand my experience as a person with mental health problems.	-.221	-.226	-.282	.601	-.052	-.136	.100	.057

<b>q10.</b> Mental health services have caused me emotional or physical harm.	-.355	-.048	-.317	.277	-.101	-.266	<b>.381</b>	-.129
<b>q8.</b> The mental health staff ignore my physical health.	-.314	.036	-.226	<b>.593</b>	-.120	-.140	.089	-.081
<b>q5.</b> I do not have enough good service options to choose from.	-.070	-.154	<b>-.713</b>	.216	-.049	-.211	.086	-.082
<b>q2.</b> Staff respect me as a whole person.	.399	.100	.135	-.141	-.115	<b>.585</b>	-.182	.072
<b>q13.</b> Mental health services led me to be more dependent, not independent.	-.033	.007	-.003	<b>.701</b>	.086	.037	.052	-.067
<b>Self-Care and Wellness</b>								
<b>q41.</b> My family gets the education or supports they need to be helpful to me.	.314	.286	.276	.147	<b>.423</b>	.040	-.202	.069
<b>q22.</b> Mental health staff support my self-care or wellness.	<b>.718</b>	.262	.089	-.169	.160	.100	-.117	-.016
<b>q35.</b> Mental health staff help me build on my strengths.	<b>.630</b>	.384	.095	-.111	.179	.114	-.111	.040
<b>q36.</b> My right to refuse treatment is respected.	<b>.740</b>	-.017	.112	.015	-.034	.141	.000	.182
<b>q40.</b> I can see a therapist when I need to.	.376	.230	<b>.411</b>	.009	.316	.094	-.218	.005
<b>Basic Life Resources</b>								
<b>q25.</b> I have reliable transportation to get where I need to go.	.153	.299	<b>.399</b>	.011	.066	-.305	.058	.119
<b>q19.</b> I have housing that I can afford.	.119	.484	.065	.046	.017	-.186	-.221	<b>.539</b>
<b>q15.</b> I have enough income to live on.	.116	<b>.675</b>	.097	.036	.011	-.136	-.082	.245
<b>q9.</b> I have a place to live that feels like a comfortable home to me.	.045	.081	.126	-.140	-.013	.155	.029	<b>.752</b>
<b>q6.</b> Mental health services helped me get housing in a place I feel safe.	.136	<b>.448</b>	.087	-.079	.301	.285	-.147	.398
<b>Meaningful Activities</b>								
<b>q23.</b> Mental health services helped me get or keep employment.	.125	<b>.644</b>	.172	-.061	.190	.155	-.031	.058
<b>q24.</b> I have a chance to advance my education if I want to.	.331	<b>.455</b>	.267	-.153	-.031	.050	.052	-.040
<b>q1.</b> I am encouraged to use consumer-run programs (for example: support groups, drop-in centers, etc.).	.105	.134	-.032	-.007	.368	<b>.611</b>	-.045	-.082
<b>q16.</b> Services help me develop the skills I need.	.247	<b>.637</b>	.136	-.187	.107	.287	-.083	-.123
<b>Peer Advocacy</b>								
<b>q26.</b> There was a consumer peer advocate to turn to when I needed one.	.252	<b>.377</b>	.376	-.068	.329	.066	-.023	.100
<b>Staff Treatment Knowledge</b>								
<b>q33.</b> Staff lack up-to-date knowledge on the most effective treatments.	-.125	-.191	-.012	.239	.055	.011	<b>.699</b>	.008
<b>Access</b>								
<b>q11.</b> I cannot get the services I need when I need them.	-.266	-.171	<b>-.575</b>	.226	-.119	-.234	.188	-.103

## ATTACHMENT 2: Rotated Component Matrix(a) ROSI 42-Item Scale

	COMPONENT							
	1	2	3	4	5	6	7	8
<b>Staff and Treatment Satisfaction Scale</b>								
q36. My right to refuse treatment is respected.	.740	-.017	.112	.015	-.034	.141	.000	.182
q28. Staff give me complete information in words I understand before I consent to treatment or medication.	.735	.015	.074	-.070	.216	.037	-.072	.105
q32. Staff listen carefully to what I say.	.734	.122	.156	-.123	.166	.091	-.064	-.005
q22. Mental health staff support my self-care or wellness.	.718	.262	.089	-.169	.160	.100	-.117	-.016
q21. Staff see me as an equal partner in my treatment program.	.706	.161	.069	-.091	.105	.158	-.261	.027
q29. Staff encourage me to do things that are meaningful to me.	.687	.280	.125	-.107	.175	.079	-.061	-.015
q31. Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual	.681	.050	.010	-.114	-.008	.098	-.139	.071
change and recover.	.673	.301	.018	-.235	.054	.036	.004	-.135
q35. Mental health staff help me build on my strengths.	.630	.384	.095	-.111	.179	.114	-.111	.040
q17. I have a say in what happens to me when I am in crisis.	.620	.240	.170	.002	-.093	.064	.088	-.055
q30. Staff stood up for me to get the services and resources I needed.	.601	.205	.232	.065	.320	.254	-.130	.111
q37. My treatment plan goals are stated in my own words.	.577	.105	.048	-.206	.360	.007	.110	.278
q38. The doctor worked with me to get on medications that were most helpful for me.	.525	.093	.358	-.015	.051	.068	-.051	-.022
q34. Mental health staff interfere with my personal relationships.	-.522	.111	-.186	-.018	-.028	.032	.326	-.063
q39. I am treated as a psychiatric label rather than as a person.	-.497	-.063	-.066	.298	-.154	.036	.376	-.100
<b>Independence Scale</b>								
q15. I have enough income to live on.	.116	.675	.097	.036	.011	-.136	-.082	.245
q23. Mental health services helped me get or keep employment.	.125	.644	.172	-.061	.190	.155	-.031	.058
q16. Services help me develop the skills I need.	.247	.637	.136	-.187	.107	.287	-.083	-.123
q24. I have a chance to advance my education if I want to.	.331	.455	.267	-.153	-.031	.050	.052	-.040
q6. Mental health services helped me get housing in a place I feel safe.	.136	.448	.087	-.079	.301	.285	-.147	.398
q26. There was a consumer peer advocate to turn to when I needed one.	.252	.377	.376	-.068	.329	.066	-.023	.100
<b>Access Scale</b>								
q5. I do not have enough good service options to choose from.	-.070	-.154	-.713	.216	-.049	-.211	.086	-.082
q4. I do not have the support I need to function in the roles I want in my community.	-.107	-.093	-.697	.190	.052	.063	-.004	-.043
q11. I cannot get the services I need when I need them.	-.266	-.171	-.575	.226	-.119	-.234	.188	-.103
q40. I can see a therapist when I need to.	.376	.230	.411	.009	.316	.094	-.218	.005
q25. I have reliable transportation to get where I need to go.	.153	.299	.399	.011	.066	-.305	.058	.119

**Invalidated Personhood Scale**

<b>q13.</b> Mental health services led me to be more dependent, not independent.	-.033	.007	-.003	<b>.701</b>	.086	.037	.052	-.067
<b>q7.</b> Staff do not understand my experience as a person with mental health problems.	-.221	-.226	-.282	<b>.601</b>	-.052	-.136	.100	.057
<b>q8.</b> The mental health staff ignore my physical health.	-.314	.036	-.226	<b>.593</b>	-.120	-.140	.089	-.081
<b>q14.</b> I lack the information or resources I need to uphold my client rights and basic human rights.	-.096	-.119	-.248	<b>.570</b>	-.096	-.183	.309	-.071

**Supports Scale**

<b>q27.</b> There are consumers working as paid employees in the mental health agency (service agency) where I receive services.	.149	.074	-.018	-.075	<b>.814</b>	.008	.145	-.016
<b>q42.</b> I have information or guidance to get the services and support I need, both inside and outside my mental health agency	.349	.279	.405	.036	<b>.472</b>	.105	-.205	.003
<b>q41.</b> My family gets the education or supports they need to be helpful to me.	.314	.286	.276	.147	<b>.423</b>	.040	-.202	.069

**Encouragement Scale**

<b>q3.</b> There is at least one person who believes in me.	.210	-.024	.141	-.262	-.107	<b>.625</b>	.120	.204
<b>q1.</b> I am encouraged to use consumer-run programs (for example: support groups, drop-in centers, etc.).	.105	.134	-.032	-.007	.368	<b>.611</b>	-.045	-.082
<b>q2.</b> Staff respect me as a whole person.	.399	.100	.135	-.141	-.115	<b>.585</b>	-.182	.072
<b>q12.</b> Mental health services helped me get medical benefits that meet my needs.	.188	.311	.288	.185	.218	<b>.394</b>	-.064	.199

**Negative Service Experience Scale**

<b>q33.</b> Staff lack up-to-date knowledge on the most effective treatments.	-.125	-.191	-.012	.239	.055	.011	<b>.699</b>	.008
<b>q20.</b> Staff use pressure, threats, or force in my treatment.	-.457	.037	-.166	.097	.089	-.135	<b>.484</b>	-.042
<b>q10.</b> Mental health services have caused me emotional or physical harm.	-.355	-.048	-.317	.277	-.101	-.266	<b>.381</b>	-.129

**Adequate Housing Scale**

<b>q9.</b> I have a place to live that feels like a comfortable home to me.	.045	.081	.126	-.140	-.013	.155	.029	<b>.752</b>
<b>q19.</b> I have housing that I can afford.	.119	.484	.065	.046	.017	-.186	-.221	<b>.539</b>

Extraction Method: Principal Component Analysis.  
 Rotation Method: Varimax with Kaiser Normalization.  
 a Rotation converged in 11 iterations